SSI DISABILITY ISSUES

HEARING

BEFORE THE

SUBCOMMITTEE ON PUBLIC ASSISTANCE AND UNEMPLOYMENT COMPENSATION

OF THE

COMMITTEE ON WAYS AND MEANS
HOUSE OF REPRESENTATIVES

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SSI DISABILITY ISSUES

MONDAY, JUNE 6, 1983

House of Representatives,
Committee on Ways and Means,
Subcommittee on Public Assistance and
Unemployment Compensation,
Hayward, Calif.

The subcommittee met at 9 a.m., pursuant to notice, in the City Council Chambers, Hayward, Calif., Hon. Fortney H. (Pete) Stark presiding.

[The press release announcing the hearing follows:]

[Press release of Tuesday, May 31, 1983]

THE HONORABLE HAROLD E. FORD (TENN.), CHAIRMAN OF THE SUBCOMMITTEE ON PUBLIC ASSISTANCE AND UNEMPLOYMENT COMPENSATION, COMMITTEE ON WAYS AND MEANS, ANNOUNCES A SUBCOMMITTEE FIELD HEARING TO BE HELD IN HAYWARD, CALIF., ON SUPPLEMENTAL SECURITY INCOME DISABILITY ISSUES ON MONDAY, JUNE 6, 1983.

The Honorable Harold E. Ford (Tenn.), Chairman of the Subcommittee on Public Assistance and Unemployment Compensation of the Committee on Ways and Means, today announced that the Subcommittee will be conducting a field hearing in Hayward, California, on Monday, June 6, 1983, on Supplemental Security Income (SSI) disability issues. The hearing will be held in the Hayward City Council Chambers, 22300 Foothill Boulevard, Hayward, California, beginning at 9:00 a.m.

The purpose of the hearing is to receive testimony from invited witnesses concerning the impact on SSI recipients of the disability reviews now being conducted by the Social Security Administration. The Subcommittee will also receive testimony on the implementation and effect of certain SSI amendments included in the Disability Amendments of 1980 (Public Law 96-265) which were intended to lessen the work disincentives for SSI disabled recipients. The authorization for these amendments expires on December 31, 1983.

H.R. 3074, which has been introduced by 16 members of the Committee on Ways and Means, would suspend the periodic reviews of mentally disabled SSI recipients. The bill also makes permanent section 1619 of the Social Security Act, added by P.L. 96-265, which provides for the continuation of special cash assistance and medicaid coverage for working disabled SSI recipients.

For more information concerning the hearing, call the Subcommittee offices at (202) 225-1025 or (202) 225-1076.

Mr. **Stark**. In the spirit of asking those people who have been good enough to come here and testify, for those of you who've not been involved in a congressional hearing before, we are trying to build a record which will be read by my colleagues' staff and summarized to my colleagues because that's how we work. We have a lot of people who digest thousands of words down to a few words for us and tell us what's important about what you're going to say.

In that spirit, I will first apologize for my colleague, Congressman Matsui, who has a rather serious illness in his family and is unable to make it this morning.

I am going to ask all the witnesses to summarize in any way they want their testimony. Allen Jensen, who is the counsel for the Subcommittee on Public Assistance and Unemployment Compensation, and I will have questions. We also may ask people to submit data for us later to include in the record and there will be hearings like this around the country. We will put together a report. If anybody is interested in seeing that final product, if they let me or one of my staff people know, we'll see that you get it. I would imagine that will be a month or so before it's printed.

That will then be the basis on which we will argue for, hopefully, progressive changes in the law.

[Mr. Stark's prepared opening statement follows:]

OPENING STATEMENT OF HON. FORTNEY H. (PETE) STARK, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

We are here this morning because we are hearing horror stories back in Washington: We are hearing horror stories about people being driven to the brink of despair and beyond, because of the inhumanity of the disability review process. We are hearing that thousands of honest and decent mentally disabled individuals are losing their benefits, because of the Social Security Administration's blind, callous, and I believe illegal budget cutting.

In 1980, when Congress mandated that disability recipients be reviewed every three years, it never intended a wholesale purge of the mentally disabled. It was guesstimated that perhaps 20 percent of disability beneficiaries were not entitled to benefits. But instead of 20 percent, the Social Security Administration has so tightened its criteria that now 40 to 55 percent of claimants are being denied their just benefits.

One study conducted by the General Accounting Office (GAO) has found that of 1,400 cases it reviewed, 9 out of 10 individuals who were denied and then appealed were ultimately reinstated! Reinstated, I might add at a terrible cost to their mental well-being and their pocketbooks. Clearly there is something wrong with a system when 9 out of 10 claimants win back their benefits. And clearly, it becomes obvious that this inhumane review process should come to a halt until reforms are made in the program.

To date, we have had very generalized studies on how mentally disabled social security disability (SSDI) individuals have been affected. We need to hear specifics on how the review process is affecting California supplemental security income (SSI) recipients and their families. Are the medical criteria being so narrowly defined that, to use one social security examiners words, a person must be "literally climbing the walls to qualify" for benefits? Are the disability determinations accurately assessing these peoples' ability to work?

We need to hear how recipients are coping with this inhumane system. What is happening to the mentally impaired when they lose their benefits? Are the costs simply being shifted from the Federal Government to the State and local levels? We need ideas on how benefits can be denied to those who are not eligible, without denying benefits to the many who truly cannot work.

In 1980, Congress also established a work incentive program for SSI recipients (called section 1619 a and b) so that they could work and still collect some cash assistance and medicaid. Unfortunately it seems that few people have applied for these benefits. I would like to know if the drive to deny, deny, deny, has had a chilling effect on this worthwhile program. For some reason, this administration just cannot stand work incentive programs. It seems they would rather see people collect larger benefits and not work. It doesn't make sense to me! I hope some of you here will have ideas on how to make this important work incentive program effective.

I along with Congressman Matsui and 14 other members of the Ways and Means Committee, have introduced legislation calling for a moratorium on reviewing the mentally disabled until regulatory reforms are made. I hope all of you will present us with testimony on whether such legislation is needed, and how we can best stop this disastrous toll on one of society's most vulnerable groups.

Mr. **STARK**. I will skip my prepared opening remarks. There are copies if anybody wishes to look through it, and introduce our first panel, who, hopefully will bring us some perspective on the statewide problem, the Honorable Senator Bill Lockyer, State senate; Greg Saunders, representing the California Association of the Physically Handicapped and the Coalition of Independent Living Centers. He has worked with us on this committee in the past and we appreciate that. Peter Breen from Marin County Department of Social Services. He's the director of that department and a member of the County Welfare Directors Association.

Senator Lockyer is doing his own research this morning on public transportation and has to catch a Greyhound for Sacramento so, Bill, why don't you proceed.

STATEMENT OF HON. BILL LOCKYER, A CALIFORNIA STATE SENATOR

Mr. LOCKYER. Thank you, Congressman. I appreciate the opportunity to appear on behalf of the State senate.

We have a group which regularly tries to address the issues involving State/Federal relations and, in particular, any impact that changes in Federal rules and regulations may have on State programs and clients that we're trying to address ourselves to their needs.

Of course, there's been considerable turmoil and a good deal of anger that has resulted from the changes in SSI and disability programs, most particularly the eligibility rules and the effort to push clients back into the workplace. I think probably it goes without saying that we'd like to see these people be employed, as would, of course, the clients that we're talking about. So the question is, how can we accomplish that in some sensible way when it is possible and not injure people when it's not.

Much of the confusion, I think it probably results from the process that was employed. That is, the use of internal rules to change eligibility rather than in the more traditional way of statutory, regulatory changes that we involve public comment periods, notice requirements, things of that sort, that tend to rationalize the process. I'm afraid much of the anger came out of the approach to it, which I assume was a political decision to minimize the amount of time that would get used in shaking the eligibility tree.

But let's look specifically at California. In this previous fiscal year, we had 70,790 cases reviewed in the State of California. Almost 30,000 of those——

Mr. STARK. That's on SSI?

Mr. LOCKYER. Combination of both; 29,284 or 30,000 of the 70,000 were deemed to be ineligible. Of that group, 21,000, approximately, are SSEI and 8,000, SSI.

Well, there have been numerous stories. I guess, perhaps, for policymakers, the most dramatic way to summarize this kind of issue is to relate some of the personal stories of human tragedy that have resulted from a loss of income. I think you will hear a number of those today so I won't do that this morning, other than to indicate that there, of course, have been just dozens of dramatic, heart-rending newspaper accounts of the impact on individual lives of those changes.

With respect to the fiscal matter that the subcommittee was particularly interested in, it seemed to be virtually impossible to get any hard, reliable specific numbers about the fiscal results of State and local government. We do have some estimations, some notions about the way in which the diminution of Federal responsibility results in an increase in State and local costs.

Mr. **Stark**. Good trick. Use your employees to reduce our costs.

Mr. **Lockyer**. I thought that was clever.

The counties estimate that general assistance costs in California have increased approximately $30 million a year, as a result of people going on those programs.

If you add to that the costs of refugee programs and terminations that are occurring there, where they shift to GA. There is another $30 million, approximately. So that's the hard dollar figures. The ones that are even harder to measure are the loss of medical benefits that results from being reviewed and dropped from the rolls. And then the resulting county hospital costs or in the case where we're talking about a significant number of these clients, folks that have need for mental health services, we're finding more and more are reinstitutionalized in expensive settings rather than, perhaps, some community treatment program.

The guidelines, themselves, seem to be subject to considerable criticism. The question of what constitutes employability has been asked considerably. There doesn't seem to be any sensitivity to the particular client's age or education or experience of what skill they may have. They are just deemed employable, even if something that they might normally work in is an industry that is recession and there is no new hiring going on but, just the same, they are expected to do that.

Several medical conditions are also not sensitively treated by the guidelines and so there seems to be particular concerns expressed by folks that are working in the areas of arthritis, respiratory ailments, epilepsy, and mental health, with respect to those clients being incorrectly treated or treated by the guidelines.

We will try to provide as specific information as we can as the numbers develop as to these State and local costs and would appreciate your sensitivity to the way the problem gets dumped on local government.

With respect to possible changes, obviously, we all have long lists of services we would like to expand or improve with limited amounts of money to do that with and so I won't spend a lot of time urging that particular course of action. I hope there will be some modifications.

The moratorium would be a useful thing to slow down this process and minimize the injury until it's thought through in a more careful way and, hopefully, the procedural guarantees that due process matters are attended to better than they have in the past.

I hope that the disability evaluators will develop some better, more objective standards that can be used in making the review determinations and, perhaps, things like the policy of nonacquiescence in court decisions could be changed. That is, the decision of the department to not care about any court orders that affect eligibility grants, unless it goes all the way to the U.S. Supreme Court. The likelihood of that happening is remote and certainly slow and to ignore numerous Federal courts that have indicated that clients were improperly damaged, I think, is a haughty attitude of the agency.

With those few thoughts about possible changes in the program, I would like to conclude by thanking you for the chance to comment.

Mr. **Stark**. Thank you very much.

Aside from we need your understanding that there are only so many dollars and to just keep shoving them around, doesn't seem to do much. I'm also concerned with—normally you're presumed in this country to be innocent and I think we've just reversed that procedure in dealing with these denials of disability, that you just throw everybody off and say, OK, those who can prove that they are still disabled will get back on and that hardly seems to me the right way to go.

Mr. **Lockyer**. Congressman, if I may, you probably have heard the statistics as to the success that clients have been having when they appeal.

Mr. **Stark**. Oh, yes, over 60 percent. And we've got the judges on commission. In other words, there is a real incentive for the judge to keep his job and to not find for the disabled person. In spite of this fact, two out of three are getting reinstated.

Greg, you're second on the list.

Greg, I am going to ask you in part of your testimony to summarize for us a little bit about the whole issue of going to work and the value, it seems to me, of people just in their quality of life, of being able to do some work and the fear—what I'm always worried about is the fear of disabled people of failure.

In other words, does the system encourage people who are disabled to get in and try? I'm afraid it doesn't. Maybe you could address this issue.

STATEMENT OF GREG SANDERS, REPRESENTING THE CALIFORNIA ASSOCIATION FOR THE PHYSICALLY HANDICAPPED, CALIFORNIA COALITION FOR INDEPENDENT LIVING CENTERS, AND CALIFORNIA STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Mr. **Sanders**. Sure. Congressman, first, I'd like to thank you for this hearing and acknowledge that in addition to the California Association for the Physically Handicapped and Independent Living Centers throughout California, I am also speaking on behalf of the State council on developmental disabilities.

I think it's interesting that approximately 5 years today, I had my first opportunity to provide congressional testimony in front of a subcommittee of the ad hoc welfare reform which, in fact, you were chairing at the time, and during those years——

Mr. **Stark**. It's been downhill since.

Mr. **Sanders**. Actually, there was quite a bit of uphill period and substantially due to your support and your colleagues back in Congress. I think we had a great deal of success in removing some of the work disincentives inherent in the Social Security Act.

Senator Lockyer, in introducing the primary issues of this hearing, focused on the function of pushing people off the program too early and trying to force them into work. My statement is about the program holding back people, people who have the desire, the ability and the commitment to work, yet lack the ability to obtain total self-support or at least lack of ability to gain self-support in the time period that is mandated by the Social Security Act.

I have submitted a written testimony which outlines the history or the problem, itself; the concerns of the 96th Congress that led up to the enactment of section 1619 of the Social Security Act and its intent to resolve the problem.

I will briefly summarize my written testimony for your information and mostly so that you can take this information back to your colleagues.

I think that the work disincentive in its most simple form, considering a severely impaired individual, perhaps an individual such as myself, with total paralysis from a traumatic spinal cord injury, assesses the benefits and services that are available which include Federal SSI and a State supplemental payment, totaling $451 per month. Complete health care, not just examinations and medications but such things as maintaining my wheelchair and prosthetic devices and, in addition to that, certain highly specialized title XX social services programs which, based on an individualized need assessment, may be as much as $830 per month for an individual.

Without giving a total summation of those figures, it's quite obvious that one cannot sacrifice that scope of benefits for the $300 a month in gross earnings that indicate substantial gainful activity. The roots of the problem appear to be the definition of disability that became a very viable part of the Social Security Act in 1954. At that time, the concept of limiting disability to those individuals unable to engage in SGA or substantial gainful activity was incorporated into the Social Security Act.

Two decades later, when the supplemental security income program became a part of the act, the definition of disability was derived on the same assumptions that were essentially two decades out of date and did not respond to the SSI and medicaid programs, which are means tested and provide a mechanism to gradually reduce benefits. Instead concepts were based on a program, the disability insurance program, in which a beneficiary receives either a full benefit or no benefit whatsoever.

I would like to make it clear that the solutions that were proposed—actually enacted by the 96th Congress—are appropriate for the SSI and medicaid and title XX programs because they are means-tested and there is no intention to imply that the same procedures that are appropriate for these programs may be appropriate and correct for removing disincentives from the title II disability insurance and the medicare programs. As advocates, we recognize that.

I think as we, as consumers, begin to explain our problem with the work disincentives, Congress was very quick to recognize the problem and I have a brief quotation, just as an illustration of how quickly and how accurately Congress recognized the problem, on the floor of the House of Representatives on August 1, 1978, Congressman Guy Vander Jagt stated, and I will quote:

> As our Welfare Reform Subcommittee moved around the country, this was the number one concern expressed to us by permanently disabled people. They want their work efforts not to be penalized by HEW regulations with a blanket rule that says "We know that you are not disabled," despite the permanent and in many

cases, agonizing disability that is apparent to anyone who would just open his eyes and see.

Now, identifying a problem doesn't necessarily mean that identifying a solution to the problem is easy. And, in fact, Congress had two concerns: One concern was that a direct revision in the definition of disability, while it would serve the purpose of allowing severely impaired persons to reduce dependency on public assistance, may also have the unintentional impact of allowing less severely impaired persons, not currently eligible, to enter the SSI program, under the revised definition.

Second, there was a concern that a definition, a revised definition of disability for the purposes of SSI program, might be construed as a precedent to revise the definition of disability for purposes of the disability insurance program. And in response to those two concerns, Senator Bob Dole in Senate bill 591, proposed that a new section be added to the Social Security Act, section 1619. In essence, section 1619 proposes no revision whatsoever in the definition of disability.

On the contrary, it provides for restricted circumstances, under which a severely impaired individual may engage in substantial gainful activity and continue to receive benefits. The cash SSI award will gradually phase out and the linkage to medicaid—essential health services with State-established standards—and the linkage to title XX social services may continue.

I think a very vitally important aspect of the background of this legislation is bipartisanship. I should point out that the coauthors of Senator Dole's bill included Senators Moynihan, Bentsen, Ribicoff, Cranston, Danforth, Schweiker, and Javits. In essence, this was quite obviously a bipartisan effort, and also in the House of Representatives, I think the bipartisan strength was incredibly overwhelming.

In the last year of the 95th Congress, the House of Representatives passed legislation targeted at this problem by a vote of 399 to 4. In the first year of the 96th Congress, the House of Representatives passed legislation by a vote of 374 to 3. I think it's particularly significant in the 96th Congress that prior to the passing of that legislation, both the ranking Republican on the Ways and Means Committee and, at that time, the ranking Democrat joined in a "Dear Colleague" letter, urging bipartisan support, which was quite obviously received.

In 1978, when I had my first opportunity to testify before the hearing you were at that time chairing, I explained the problem and I believe I concluded by saying that our desire is simply to be productive and participating citizens of society and that we want to work, we have ability to work and I believe my words were, "For God's sake, let us work."

At this time, and with intense sincerity, I can say that those individuals who are seeking continuation of section 1619 of the Social Security Act which is due to sunset January 1, 1984, are looking at the progress over the past years, and see that in ever-increasing numbers, severely impaired are, in fact, entering the work force and are proving themselves to be competent and effective and reliable workers.

I can meaningfully revise my statement at this time to say that we are working, and for God's sake, let us keep working. I don't believe that, on our own, we can eliminate a $200 billion deficit; but I do believe that, by allowing us to support ourselves, we can help in our own way.

Since there are a number of witnesses who can obviously add detail to case examples, and so forth, on both the issues that I've raised and Senator Lockyer raised, I believe I will conclude my testimony at this point and again, thank you.

[The prepared statement follows:]

STATEMENT OF GREG SANDERS, CENTER FOR INDEPENDENT LIVING

I would like to begin my testimony by sincerely thanking Mr. Stark and Mr. Matsui for conducting this hearing. My gratitude and my technical comments which are being stated today are shared by the California Association for the Physically Handicapped, the California State Council on Developmental Disabilities and independent living centers throughout the State.

Both the 95th Congress and the 96th Congress seriously studied the issue of technical barriers inherent in the language of the Social Security Act which prevented disabled Supplemental Security Income (SSI) recipients from attempting and maintaining employment. Recognizing the significance and urgency of this issue the 96th Congress prioritized legislation targeted at SSI recipients who strived to reduce their dependency on public assistance by performing substantial work despite a severe medical impairment. The House of Representatives responded conclusively to the need to resolve the existence of technical work disincentives by passing legislation (H.R. 3464) with a vote of 374 ayes and only 3 nayes. Following an equally strong commitment in the Senate to remove this dilemma for severely impaired citizens, legislation was refined in conference committee and ultimately signed into law (Public Law 96-265) on June 9, 1980.

Before I address particular aspects of Public Law 96-265, the Social Security Disability Amendments of 1980, I believe it is important to briefly describe the technical barriers to employment referred to by SSI recipients as "work disincentives," and to discuss the general intent of Congress which generated the provisions of the 1980 Amendments which attempted to remove these disincentives.

First, I must emphasize that this statement exclusively addresses Supplemental Security Income, Medicaid and Title XX of the Social Security Act. Due to the fact that SSI and Medicaid contain a means test for income and resources, solutions to the issues of work disincentives that are effective and appropriate for these programs may not be appropriate for the Disability Insurance (DI) or Medicare programs which are intentionally designed not to contain a means test.

Supplemental Security Income, Medicaid and Title XX Social Services serve a very fundamental purpose—they provide for essential maintenance and health needs. SSI provides for necessary food, clothing and housing. Medicaid provides basic health care as well as medically related items like prosthetic devices and specialized services such as in-home personal care attendants. Title XX provides a range of supportive services which may include job supervision for mentally retarded persons, mobility instruction for the visually impaired, homemaker services, etc. (Since Medicaid and Title XX are substantially affected by state-established standards, some services of major importance such as attendant care may be provided through Medicaid in some states and through Title XX in other states.)

For a particular individual in California with a severe impairment, perhaps an individual like myself who is permanently paralyzed from a traumatic spinal cord injury, the scope of services available from SSI, Medi-Cal (California's Medicaid program) and Title XX social services may include:

(a) an SSI/SSP income maintenance grant of $451 monthly:

(b) health coverage for medical examinations, acute health care, Wheelchair purchase and maintenance, medications etc., and,

(c) Title XX funded In Home Support Services with a maximum grant based on individualized need assessment of $838 or other specialized social services.

The significance of these programs is, certainly, not limited to maintaining recipients in a healthy living arrangement. The combination of income maintenance, health coverage and social services support an environment where an individual with a severe physical or mental impairment can pursue vocational rehabilitation or habilitation and, ultimately, employment. The current quality of services and technology create the very real opportunity for the great majority of citizens with severe impairments to seek meaningful work activity. The dilemma of the work disincentives becomes clear when the opportunities created by the scope of current programs are blocked by concepts of disability which were dominant in the 1950's and remain in federal law. The term "disabled" became a viable part of the Social Security Act in 1954. When the Supplemental Security Income Program was implemented in 1974 it based the definition of "disabled" on the assumptions derived two decades earlier.

Section 1614 of the Social Security Act establishes that a disability can exist only if the individual is unable to engage in "substantial gainful activity" (SGA). The level of work activity which indicates SGA is prescribed in regulation by the Secretary of Health and Human Services. Currently SGA is indicated by services performed which represent the ability to achieve gross earnings of $300 per month or by earnings derived from employment which exceed $300 per month. The ability to perform work activities is the basis for determining SGA. It is not necessary for an individual to receive payment or to actually perform any activities to be judged *able* to engage SGA. Most importantly, disability status will cease due to performance of SGA regardless of a severe impairment which is demonstrated by medically acceptable clinical and laboratory diagnostic techniques.

The SSI and Medicaid programs do have a mechanism to gradually reduce the level of benefits and services as income available to the recipient increases. Yet, the termination of disability status when earnings reach the SGA level causes an abrupt end to the gradual reduction process. The complete loss of SSI, Medicaid and linked social services due to a cessation of disability status requires the disabled individual to limit attempted work activity to services which do not indicate SGA, or to obtain employment which provides sufficient net income to replace all of these necessary services.

While some exceptional individuals can attempt a sudden transition from SSI status to self support, it is unrealistic to expect such action from the majority of persons with severe impairments. Similar to the typical unimpaired worker, the disabled employee will usually enter employment at a low level and work up a career ladder. Although a disability may not preclude the ability to pursue employment, a mental or physical impairment may certainly inhibit the ability to obtain rapid advances in the work force. For the physically impaired, developing stamina and learning to accommodate architectural barriers are as important as acquiring vocational skills. Likewise, cognitive ability is an important factor in determining the level of employment obtainable for the mentally impaired individual and the time necessary to acquire skills.

The work disincentive created by the definition of disability in section 1614 of the Social Security Act can be accurately summarized in a single statement. Since the combined fiscal value of the SSI/SSP income maintenance grant ($451 monthly) health coverage, and social services (as much as $838 monthly for some individuals), cannot be sacrificed for gross earnings of $300 monthly the severely impaired SSI recipient simply cannot afford to attempt employment that indicates the ability to perform substantial gainful activity. As Congress solicited testimony regarding Welfare Reform (HR 9030) they recognized the reality of the "work disincentive" inherent in the definition of disability. Mr. Vander Jagt acknowledged this fact in discussion on the floor of the House of Representatives on August 1, 1978, when he stated: "As our Welfare Reform subcommittee moved around the country this was the No. 1 concern expressed to us by permanently disabled people. They want their work efforts—and sometimes they are heroic efforts—not to be penalized by HEW regulations which amount to a blanket rule that says, we know you are not disabled, despite their permanent, and in many cases agonizing disability, that is apparent to anyone who would just open his eyes and see". However, understanding a problem does not necessarily mean that a solution to the problem can be easily determined. In fact, Congress was concerned with two very valid issues which would accompany a direct revision in the definition of disability. Those concerns were:

(a) A revision in the definition of disability intended to enable severely impaired SSI recipients to gradually reduce their dependency on public assistance by engaging in employment may unintentionally allow less severely impaired individuals who are not eligible for SSI to actually increase their dependency by entering the SSI program under the revised eligibility criteria; and,

(b) A revision of section 1614 of the Social Security Act which defines disability for purposes of the SSI program may be incorrectly interpreted as a precedent for similar revision in the section of the Social Security Act which defines disability for the purposes of the Title II Disability Insurance programs. After substantial consideration, Senator Dole introduced legislation (S. 591) which was specifically designed to remove the work disincentive for severely impaired SSI recipients in a manner that was very acceptable to Congress. To illustrate the strong, bi-partisan support for S. 591 it should be noted that the legislation was co-authored by Mr. Moynihan, Mr. Bensten, Mr. Ribicoff, Mr. Cranston, Mr. Danforth, Mr. Schweiker and Mr. Javits. S. 591 did not propose a revision in the definition of disability. On the contrary, the bill proposed that a new section, Section 1619, should be added to the Social Security Act. In essence, Section 1619 established very restricted circumstances under which an SSI recipient could continue to receive benefits if they engaged in Substantial Gainful Activity despite a a severe medical impairment.

Title II, section 201, of Public Law 96–265 contained the language proposed by Senator Dole and his colleagues with one very important exception. Although S. 591 proposed section 1619 as a permanent provision of the Social Security Act, Title II, section 201(d), of Public Law 96–265 provided that Section 1619 of the Act shall remain in effect only for a period of three years. Accordingly, Congress must act to continue Section 1619 of the Act prior to January 1, 1984, or the exhaustive efforts of the 95th Congress and 96th Congress to remove the work disincentive for severely impaired persons will become meaningless.

By establishing a sunset clause for Section 1619, PL 96–265 simply intended to assure that no unforseen problems would arise. Thus, PL 96–265 required a report from the Secretary of HEW (HHS) on the impact of Section 1619. Additionally, PL 96–265 authorized funds for pilot projects to determine if a better means than Section 1619 could be identified to eliminate work disincentives.

Unfortunately, funds were not appropriated to conduct the intended pilot projects and the required study failed to identify many individuals who were eligible for continued benefits under Section 1619 Part (A) or Part (B). Since following witnesses in this hearing will present case examples which illustrate the problems with the study, I will not elaborate on this point. I will, however, emphasize that Section 1619 restricts continuation of benefits to SSI recipients who could not continue their employment without the supplemental assistance received from Part (A) or Part (B) of the Section. On this basis, the Department of Health and Human Services should not focus on benefits paid to persons covered by Section 1619 but, from the correct perspective, should state the savings attributed to the provisions of Section 1619. Since the absence of Section 1619 which enables recipients to gradually reduce SSI/SSP payments would, by definition, force the recipient to abandon employment and accept total dependency on public assistance, it is only logical to assess the impact of the Section in terms of savings to the federal and state governments.

I will conclude my discussion to this aspect of the 1980 Amendments by referring to Mr. Vander Jagt's statement which I quoted earlier. In regard to permanently disabled persons, the Congressman stated: "They want their work efforts—and sometimes they are heroic work efforts—not to be penalized by HEW regulations."

I wish to stress to the Members of Congress that the severely impaired SSI recipients who seek continuation of Section 1619 of the Social Security Act have no desire to be heroes. With intense sincerity, we simply want to be average, productive citizens who can be proud participants in the mainstream of our great American Society.

Mr. STARK. Greg, thanks very much, again. If you will stay here we will ask Mr. Breen if he'd like to summarize for us his testimony this morning and then we'll talk a little about the issues you've raised.

STATEMENT OF PETER BREEN, DIRECTOR, MARIN COUNTY DEPARTMENT OF SOCIAL SERVICES, ON BEHALF OF THE CALIFORNIA COUNTY WELFARE DIRECTOR'S ASSOCIATION

Mr. BREEN. Thank you, Congressman Stark.

My name is Peter Breen, county welfare director, Marin County, Calif., and I am here today representing the California County Welfare Director's Association.

The counties have been severely affected or impacted by the cessation of benefits to some 29,284 individuals that Senator Lockyer spoke about in 1982.

As you're aware, local government has been greatly restricted in its ability to generate new revenues since the passage of proposition 13, yet in California, each county must still provide for its indigents, using the local property tax dollar.

The inappropriate cost shift to counties in terms of general assistance payments ranges from $10.9 million to $30.8 million. I might point out in my written testimony, there has been a mistake. There are some zeroes missing from it.

The wide difference in our estimates is because we've not been able to track on a statewide basis the 29,000 discontinued individuals in our county-administered system. Our conservative estimate is that between one-half and two-thirds of those discontinued do receive county assistance from 3 to 6 months, as their cases wend their way to the appeal process.

Since general assistance payments usually are one-half of the SSI payment, longstanding, usually cost-beneficial housing arrangements are disrupted, many times forcing the recipient to transient and unstable housing situations—as an aside, I can cite a case in our own county of one discontinued recipient who frequently moves between San Francisco and Marin housing shelters, as 1-night plans can be made. She transfers her entire belongings on the bus.

The injustice to the recipient and the local taxpayer is that 91 percent of those cases reaching the administrative law judge are indeed restored. A further injustice and probably a greater injustice is the one that befalls the mentally impaired individuals who simply don't know what to do when they are terminated and don't even appeal until they come to the local welfare department to receive some kind of assistance.

Several counties—notably Sacramento, Alameda, Los Angeles, Fresno, and San Diego—have even established special workers or units of workers whose sole duty is to assist terminated recipients through the appeal process. Although these units are funded locally, continuing general assistance cost-avoidance warrants our expenditures of the local funds.

Now, to hidden costs. Aside from the direct cash assistance payments, which I mentioned, range from $10 to $30 million, the counties are now absorbing significant other costs in caring for discontinued recipients. Our adult protective services referrals funded under title XX are on the rise, especially regarding the 25- to 59-year-old single adults who move from crisis unit stays to unstable living arrangements, back to crisis unit, caught up in this round-robin of uncertainty and fear.

Medical care now in California for terminated individuals is sporadic, at best, since the discontinuance of the medically indigent program in California, effective January 1. That's the program that was transferred back to the counties at 70 percent of the 1982 funding and counties are finding it extremely difficult to provide appropriate and full service to these individuals.

All in all, I think, in summary, the situation facing the counties as a result of these inappropriate terminations, clearly documented in the study recently conducted by the GAO's office, is not good.

Our association has actively supported the congressional actions to remedy the problem. Public Law 974–55 is the beginning and we're supportive of H.R. 3074 and are willing to work with your staff to whatever end, to bring relief to the unfortunate terminees and also to the unfortunate, beleaguered counties. Thank you.

[The prepared statement follows:]

STATEMENT OF PETER BREEN ON BEHALF OF THE CALIFORNIA COUNTY WELFARE DIRECTOR'S ASSOCIATION

Good morning, my name is Peter Breen, County Welfare Director of Marin County, California, representing our statewide California County Welfare Director's Association.

In view of the time constraints this morning, and in view of other testimony already offered regarding the deficiencies in the continuing disability investigation process, particularly as it relates to the mentally impaired, our testimony will relate to the impact on the counties.

California's counties have been severely affected by the termination of benefits to some 29,284 recipients in fiscal year 82 alone. As you are aware, local government has been greatly restricted in its ability to generate new revenue since the passage of Proposition 13. Yet, in California each county must provide for its indigents, utilizing local property tax dollars.

The inappropriate annual cost shift to counties in terms of General Assistance payments ranges from $1.9 to $3.8 million dollars. The wide difference in our estimate is because we have not been able to track, on a statewide basis, the 29,284 discontinued cases in our county administered systems. It is our conservative estimate that between one-half to two-thirds of those discontinued do seek county assistance from three to six months as their cases move through the appeal process. Since General Assistance payments average less than one-half the SSI payments, long standing, usually cost beneficial and secure housing arrangements are disrupted, many times forcing the recipient into transient and unstable housing situations. (As an aside I can cite a case in our county where one discontinued recipient frequently moves between San Francisco and Marin housing shelters as one night plans can be made. She transports her entire belongings with her on the bus.) The injustice to the recipient and the local taxpayer is that 91 percent of those terminated cases reaching the Administrative Law Judge level are indeed restored. The further injustice, and probably greater, is that which befalls the mentally impaired terminated recipient who simply doesn't know what to do and does not even appeal until they come into a local welfare department for help. Several counties (Sacramento, Alameda, Los Angeles, Fresno, San Diego and others) have established special workers or units of workers whose sole duty is to assist General Relief applicants through the appeal process. Although these units are funded locally, the continuing General Assistance cost-avoidance element warrants our expenditure of local funds.

Aside from direct cash assistance, counties are now absorbing significant other costs in caring for discontinued recipients. Our Adult Protective referrals are on the rise, especially regarding the 25-59 year old single adults who move from crisis unit stays to unstable living arrangements, back to crisis unit stays to unstable living arrangements, back to crisis unit stays. Medical care is sporadic at best, since the discontinuance of the Medically Indigent Adult program and transfer back to the counties January 1, 1983.

All in all, the situation facing the counties as a result of the rash of inappropriate terminations, clearly documented by a recent study conducted by the General Accounting Office, is not good. Our association has actively supported congressional actions designed to remedy the problem. Public Law 97-455 was simply a beginning and we support and are willing to work with your staff to whatever end to being relief to both the unfortunate "terminees" and the financially beleagured counties.

Thank you.

Mr. **STARK**. Thank you. Peter, where did the 91 percent come from?

Mr. **BREEN**. That's out of the GAO study. That's those who reached the administrative law judge level.

Mr. **STARK**. Oh, I see.

Mr. **BREEN**. Once they get to that level.

Mr. **STARK**. And the total is around 60 percent.

Mr. **BREEN**. Right.

Mr. **STARK**. I appreciate your taking the time to outline the situation for us. It confirms what we all suspect, people in America still aren't willing to just watch people starve for supper. The idea that you can suddenly just withdraw funds and the problem will disappear is what we have so much trouble with—it's a concept that when you or I are pressed to think about it, I can't see the logic process to come to that conclusion.

But if you don't think very much about it and you're only concerned about catching the cheat—and I get letters from my constituents all the time and newspaper articles from them about the horror stories of the cheat and I keep looking because I'm going to make a citizen's arrest when I find this cheater—it will make all of our lives easier—then perhaps you can accept the program as it is now conducted.

Mr. **Breen**. That's the environment in Marin and it's a very difficult one, especially at the local level, when we're confronted with the individual and the conflict of where do you put your local priorities. I think most of the counties have decided to put their priorities here and fight, and we are fighting.

Mr. **Jensen**. Greg, you had indicated through earlier conversations that you felt the people at the district office of Social Security didn't really know too much about section 1619, provisions to provide work incentives.

Do you find that also true in other professionals that work with the disabled and the people that come to the Center for Independent Living, are you the primary source of information about that opportunity?

Mr. **Sanders**. I would suggest that Independent Living Centers, in general, throughout the State of California, and the California Association of the Physically Handicapped have done what they can to inform the disabled community that the opportunities to work under the 3-year provision of section 1619 of the act exists.

We've had incredible problems with information in the SSA district offices and the problems appear to be so widespread that it's certainly not an employee problem but a training problem. I think the very best way I could demonstrate that is to discuss my own case. As you know, I was very much involved with the development of Public Law 96-265. When, in fact, my turn came to engage in substantial gainful activity, I reported to the Social Security Administration of my work activity and, of course, my disability insurance benefits were stopped. I actually took with me the claims manual transmittal, defining section 1619 (a) and (b) and suggested that they should perform a continuing disability investigation to determine my continuing eligibility under that section of the act for my SSI grant.

That was more than 1 year ago and to this date they have never conducted a disability insurance investigation. I don't believe in those types of coincidences. I believe if an individual with that type of information can go into the district office and actually inform the district office that they are eligible for programs and there is no followthrough, then there must be a problem nationwide that district offices simply are not aware of, or not informing clients, disabled or severely disabled or potentially eligible clients, of this provision.

I might also add that in 1981, I had the opportunity to speak with a representative from the GAO and he suggested—well, he had had discussions with a high-ranking official of the Social Security Administration and he asked, "Well, why isn't there a pamphlet that describes this provision?" One response was that it's a 3-year provision and until it becomes a permanent part of the Social Security Act, there is some skepticism that the Social Security Administration will, in fact, produce the written information in the pamphlets to inform individuals.

The second comment which I found rather surprising was the Social Security Administration official said, "Frankly, there is not a pamphlet because I helped write the law and I don't understand it."

At that time, it appeared that section 1619, in its intent to address the concerns of the Congress, was complex yet 2 or 3 years into the process, we're now learning that it's really very simple. One simply needs to be informed that there are restricted circumstances, that you must have limited resources, that your earnings must not be sufficient to replace the benefits you are eligible for from other programs and under those circumstances, you can gradually phase off the SSI system.

I think if that simple message was delivered to clients, the fear of what might happen if you attempt employment would be substantially lessened. We also have a problem in that, although the original Senate legislation proposed that section 1619 would be permanent, title II, section 201(d) of Public Law 96-265, provided for the sunset clause in January 1984, and at this point, there are very few individuals who are willing to engage in substantial gainful activity and take the risk that Congress will not act before this clause sunsets and, suddenly, they will have demonstrated the ability to engage in SGA. They may be earning $500 or $600 a month and come January, they are going to lose $1,300—$1,400 worth of benefits. The concept of a 3-year study program just simply didn't work.

Most significantly, I think, by definition, an individual is not eligible for section 1619, unless failure to continue benefits would force them to abandon employment and I think that the Department of Health and Human Services should shift their focus from stating costs associated with section 1619, to stating savings attributed to section 1619 because, by definition, if 1619 doesn't exist, instead of being employed, I am going to be forced to be a full dependent on the SSI and SST programs.

Mr. STARK. We often say that the budgeteers know the cost of everything and the value of nothing. It's difficult sometimes to get that through.

Thank you both very much. I appreciate it and your entire testimony will be part of our record.

Our next panel includes Stephen Bischoff, executive director of the Mental Health Association of Alameda County; Dan Jordan, executive director, Mental Health Advocates, Oakland; Sheila Martinsen, representing the Alliance for the Mentally Ill; and Gilford Eastham, director of government affairs, California Association for Retarded Citizens.

Mr. Bischoff, why don't you proceed.

STATEMENT OF STEPHEN BISCHOFF, EXECUTIVE DIRECTOR, MENTAL HEALTH ASSOCIATION OF ALAMEDA COUNTY

Mr. BISCHOFF. Thank you. I really appreciate the opportunity to speak today.

As you might gather, the fact that I work for a mental health association, I'm going to confine myself to issues concerning mentally disabled individuals.

Our association has long been concerned about issues around disability benefits to persons disabled by mental illness. In fact, I think that we started to work on some of these issues before the transition away from the old ATD program in 1974. Our special concern at that time—and it obviously still an ultimate concern—is that one of the things that happened in that transition, as you will recall, is that the end of the provision of social workers or other persons to help people with processing around benefits really occurred at that time.

Under the ATD program, you did have social workers, you did have people who could assist people from inside with the process. And one of our main concerns with the transition to the SSI program was the elimination of those persons.

That has been a continuing problem. I think probably the major continuing problem, as I see it, anyway, has been with the whole process of so-called deinstitutionalization. SSI and SSDI are really critical to the community survival of persons suffering from mental disability. And, yet, the Social Security Administration has really demonstrated a lack of sensitivity to the meaning of mental disability and to what the lives of those suffering by it are like.

Since the program—certainly been accentuated in the last few years—there seems to be some expectation on the part of the Social Security Administration that persons suffering from a mental disability should be able to work as well with the bureaucracy as anyone else. I think there's been an implicit assumption, too, that mental disability probably would just go away at the time, leaving the former recipient really ready, somehow, to return to work or, in many cases, really, to have to begin work since many recipients of SSI never have worked.

I think there is an underlying assumption now that's probably more accentuated, which is that somehow mental disability is really a moral choice and that if people could just shape up, they'd really do OK, so the best thing to do is cut people off the rolls and then they will shape up and then they won't have the need for money.

Mr. STARK. I have always been afraid to voice that opinion but I certainly share it with you.

Mr. BISCHOFF. It's one of the things that's very obvious in the whole area of mental health. I think it's partially to give people the benefit of the doubt. I think it has a lot to do with our lack of understanding of mental illness when it all comes down to it.

Major mental illness, we do not know the cause of, we do not know cures for. And it is a sort of fear-surrounded, very stigmatized kind of thing and I think one of the presumptions that becomes obvious to you over time, if you work in this field is that sort of moral decision that people could be OK if they just really wanted to.

My fellow panelists are certainly more prepared to speak on a number of these issues than I am but I would like to say a couple of other things.

One is that we are very pleased to see H.R. 3074 and it is something that we will do our best to support the passage of. Obviously, one of the most important provisions is the provision for termination of CDI's until the criteria can be developed.

There are several other very important ideas in this bill, I think, though. One is the provision for evaluation by psychiatrists or psychologists so that there is some real qualification to assess mental disability.

Mr. **Stark**. Does that slow the process down? If you get bunching in these terminations, does that present an impediment to getting things done?

Mr. **Bischoff**. If there are these kind of more expert evaluations?

Mr. **Stark**. I'm worried that there may be people who could do some of the initial screening for them and you're talking about 30,000 people getting kicked off the rolls in California. Summarily, do we have the professional staff to go through and screen quicker?

Mr. **Bischoff**. Well, I think if some of the other ideas that are contained in your legislation and this proposal by the coalition of national organizations were adopted and it were possible to pay people a more decent fee for doing these evaluations—because one of the things that really gets ridiculous about this is what doctors often get as a consultative fee, I think you would find that there was manpower to process these.

It might slow things down in the short run, but it's one of those kind of issues where I think you have to assess the human cost first and since human suffering has been greatly increased already by actions that have been taken, I don't think it would be too terrible if people got paid benefits for a longer period of time while these determinations were made.

I think the idea of continuing benefits during an appeal is a very important idea and there are a number of other really good ideas in there but there is one I would really like to emphasize because it's something I thought about and been concerned about for a long time.

I think the idea of providing assistance to disabled individuals in their dealings with the Social Security Administration is a really critical idea and one I hope much more will be made of because we do have and have had since, actually since the SSI program started, the mental health advocates program that Dan Jordan is here representing today.

We've been extremely aware of the need of recipients for assistance and I, personally, often felt kind of guilty because I know that the level of assistance that's available, at least in part of Alameda County, is not available in many other places and I often wonder how people, you know, are able to deal with a bureaucracy like social security without that assistance.

I think that commonsense, which is something that oftentimes seems to be lacking in the dealings of social security, maybe many other administrations, too, would indicate that a person who was supposedly mentally disabled might need some assistance in dealing with this bureaucracy.

I think that, aside from the obvious implication of mental disability, the fact is that many people who suffer from mental disability, otherwise function fairly well, in general.

But many people in that situation, and I think some of it has to do with the kind of marginal economic license dictated by the level of these benefits, also live on a very thin edge and may not cope at all well with the anxieties produced by someone saying, "Well, OK, looks like you're fine, we're going to take a look at your benefits and we probably will cut you off."

I think another factor is that a significant number of persons suffering from mental disability, like the general public, do not really like to consider themselves that way. They don't like to believe that they are mentally disabled. And there are some people suffering from mental disabilities who really do not believe they are mentally disabled. People in either of these categories may have a hard time without some really sensitive assistance in making the appropriate kind of case for themselves.

Of course, the tragedy is if they can't make that kind of case for themselves because they really are mentally disabled, they then have nothing.

I wish I could say more about this but I think we'll hear more about it but I am very pleased, personally, to see the provisions for assistance in this legislation. I hope that it's something that as maybe some thought of really caring more about people who are suffering in our society reemerges, that this is an area in which more attention can be given and maybe some funding can be given to provide that there really will be that kind of assistance available in general to persons who are receiving disability benefits or applying for same.

Thank you very much.

Mr. **Stark**. Thank you.

Dan Jordan.

STATEMENT OF DAN JORDAN, EXECUTIVE DIRECTOR, MENTAL HEALTH ADVOCATES, OAKLAND, CALIF.

Mr. **Jordan**. Good morning. My name is Dan Jordan. I am director of Mental Health Advocates. We're a nonprofit agency in Alameda County that provides individual advocacy services to adults in this county.

In the range of services that we provide our clients, we assist most with helping secure benefits or maintain their disability benefits in order that they may survive in the community, versus in a hospital setting.

I am here today to shed light on some of the problems that clients encounter trying to maintain their benefits when they undergo the CDI process or continuing disability investigation.

Our agency represents many of these mentally ill clients in their appeals before administrative law judges at the Office of Hearing and Appeals.

The recently accelerated CDI process has resulted in numerous mentally ill adults facing uncertainty of knowing their survival income is going to end at some point in the immediate future. When an individual receives their notice of planned action, it tells them that their benefits will end in 1 or 2 months, it begins a cruel and lengthy process for that person.

For some, I'm sure, they never even realize they have the right to an appeal of that decision. For those who do appeal, there begins the wait of usually 4 to 6 months to which time they have an opportunity to go to a hearing and present their side of the story as to why they are unable to work.

I think this is the first time that a person has ever had a chance to face someone on a face-to-face basis and tell them why they can't work, other than the maybe 15 to 45 minutes they may have spent with the doctor on their consultative exam.

It is tragic that only after this level of the hearing is a judge able to correct a mistake that could have been avoided in the first place. If only there had been enough time and adequate preparation to deal with the evaluation in the first place.

I'd like to give you two examples of cases that our agency has represented and taken to the administrative hearing and kind of bring home some points about the whole disability evaluation process.

First case involves a man, male, age 61, who had a history of severe depression and had been on SSI since 1974. He had a high school education and was not currently under treatment. He went to the consultative exam and the doctor made the following conclusions—and this is the doctor that was contracted by Social Security:

> He has taken care of himself adequately but has a tendency for depression under stress. Although he has the ability to relate to people under a comparative employment situation, he might get depressed and disorganized. I consider this prognosis as guarded.

At the advice of his pastor, who had known him for the last 12 years, he came to us for assistance with his appeal. He was reinstated his benefits after going through 6 months of uncertainty wondering if his benefits would continue at all.

The second case I want to bring up is a case of a 32-year-old female who had been on SSI since 1971, and this was her first reevaluation, by the way. She had an extensive history of psychiatric problems since age 14. She had numerous hospitalizations with durations of from 1 to 6 months length. Her problems consisted of daily hallucinations and inability to concentrate or focus her thoughts. She had been in therapy of varying types, including receiving 35 electroshock treatments.

Based on the evidence that we were able to gather before the hearing and submit to the administrative law judge, he was able to grant a favorable decision on the record, without the need for an oral hearing. During the 5 months of waiting, the client decompensated to the point that she almost needed hospitalization.

I have some specific recommendations. I think the first is, of course, go ahead with the moratorium. I think there needs to be some time to think this process through. I think another thing is we have to look at the caseloads that disability evaluators are getting because of this accelerated process.

I think one thing that has to be done is just reduce the number of cases that someone has time to work on and also do not give them time frames of how soon they have to get a case cleared off their desk.

I think another requirement should be is to have some training for the disability evaluators done by community mental health people who work with chronically mentally ill on a daily basis and can give them an idea of what it is like to see this type of person and why this person can't work.

A third recommendation I have is that when you're dealing with cases involving psychiatric disabilities, or emotional disabilities, or mental illness, that you have these cases reviewed by psychiatrists at the State agencies so it's possible to insure adequate interpretation of the evidence and there maybe you'll have better decisions.

I think also when we talk about looking at the whole system in general, it's been mentioned some things about the trial work period. I think that when we look at a trial work period that it only involves 9 months of a person's chance to try and do some work. We have to look at extending that, maybe to between 18 and 24 months.

I've always had a question of my own, when we look at a substantial gainful activity level of $300 per month, why is there a level saying if you could earn $300 a month, you're no longer disabled, yet at the benefit rate pays somewhere around $451. I would hope that maybe some point could be made to change that substantial gainful activity level to the level of benefits.

I think another concern that comes out when people are trying to go to work or when they are worried about being cut off is just the fact of their medical coverage. A lot of times, the issue of medial. If I go to work, I try to work, what happens if I get my job and then I lose my medial? How am I going to pay for my medication and still maintain my work?

I'd like to thank you for the opportunity to come today and if Sheila would like to go next or if Pat, who has come with me today, would like to give some testimony, I think it would shed some light.

[The prepared statement follows:]

STATEMENT OF DAN JORDAN, DIRECTOR OF MENTAL HEALTH ADVOCATES

Good morning! My name is Dan Jordan, I am the Director of Mental Health Advocates, a non profit agency in Alameda county, that provides individual advocacy services to mentally ill adults in this county. In the range of services we provide to clients, we assist most with help in securing and maintaining disability benefits in order that they may survive in the community. I am here today to shed light on the many problems that clients encounter in trying to maintain their benefits when they undergo the Continuing Disability Investigation (CDI) process. Our agency represents many of these mentally ill clients in their appeals before the Administrative Law Judges at the Office of Hearings and Appeals.

The recently accelerated CDI process has resulted in numerous mentally ill adults facing the uncertainty of knowing if their survival income is going to end at some point in the immediate future. When an individual receives their Notice of Planned Action and it tells them that their disability has ended and that they will not be receiving their monthly check in two months it begins a cruel and lengthy process for that person. For some I'm sure they never even realize that they even have a right to appeal such a notice. For those that do appeal there begins the wait of usually 4 to 6 months until which time they have the opportunity to go to a hearing and present their side of the story as to why they are unable to work. This is the first time that that person has ever had a chance to tell a person face to face why they can't work, other than the 15 to 45 minutes that they may have spent with the doctor that they have seen on the exam that was required by Social Security as part of the CDI. It is tragic that only after this level is a judge able to correct a mistake that could have been avoided in the first place if only there was time enough taken to do a complete and fair evaluation of all the factors that make a fair determination possible.

Following are some examples of cases in which benefits were threatened to stop due to the CDI process:

Case No. 1: This male, age 61, had a history of severe depression and had been on SSI since 1974. He had a high school education and was not currently under treatment. He underwent a C.E. and the Doctor that saw him made the following conclusions; "he is taking care of himself adequately, but has a tendency for depression under stress. Although he has the ability to relate to people, under a competitive employment situation he might get depressed and disorganized. I consider his prognosis as guarded."

At the advice of his Pastor, who had known him for the past 12 years, he came to us for assistance with his appeal. He was reinstated his benefits after going through 6 months of uncertainty if his benefits would continue.

Case No. 2: This 32 year old female had been on SSI since 1971. She had an extensive history of psychiatric problems since age 14. She has had numerous hospitalizations with durations of one to six months in length. Her problems consisted of daily hallucinations and the inability to concentrate or focus her thoughts. She had been in therapy of varing type including receiving 35 electro shock treatments.

Based on the evidence that we were able to gather before her hearing, the Administrative Law Judge was able to grant a favorable decision on the record without the need for an oral hearing. During the 5 months of waiting the client decompensated to a point of almost needing hospitalization.

My Recommendations:

Allow the Disability Evaluators enough time on cases to do adequate development of the cases (by not overloading them.)

Provide training to the State Agencies by community mental health staff that can give them a real idea of why chronically mentally ill are not able to work.

Require that cases involving the Mentally ill be reviewed by psychiatrists at the State agencies to possible insure that adequate interpretation of the evidence is done.

STATEMENT OF PAT WRIGHT, HAYWARD, CALIF.

Ms. WRIGHT. I would like to discuss my experience with attempting to get disability and also of the process for re-evaluation.

Prior to becoming disabled in 1975, from a serious car accident and previous to that having cancer, I had been a professional nurse, registered nurse. I had worked in administration, had set up clinics myself, been supervisors of hospitals, et cetera, for 15 years prior to becoming disabled.

I was also a student at UC-Berkeley, going on scholarship, studying business and law and economics and I substantiated that also by working and supplied my own funds, so that I wanted to show that I am not a stereotype person and I attempted to get disability for 2½ years after my accident and I finally had to go to court, where it was proven that I had 12 individual things that qualified me for disability, both physical and mental disabilities.

During that 2½ year period, I attempted to work and for the first time in my whole life, I was fired five times. Because of that one thing—being fired five times, I'd never ever had an experience of being fired from anything in my whole life, I was a straight "A" student, I had excellent qualifications and everything—that set up a problem that if I am able to work again, what kind of recommendations do I use? My school, which I was a straight "A" student, because I didn't qualify for disability and had no grants for receiving special attention, I've gone from a straight "A" student to an "S" student, but I was at least attempting to go to school.

After receiving the judgment of disability from the court in April 1982, it took 7 months to November 1982, for me to finally receive my first check. During that time, I had to use what savings I had during the 3 years of waiting. I subsequently lost my house and other property that I had gained when I was working. When I received my notice of reevaluation, during that time, I was going to Bankruptcy Court for a final hearing, which I lost my property and the house. I received the notice on April 5, that I was going to be reevaluated.

That was only 5 months after I received my first check. The trauma of having to do that—and I absolutely hate, as you can imagine from my background, going to the social security office, being treated as though I didn't deserve to get this or to have it. And also because I am receiving $536 a month, I have a liability of $198 a month in order to get Medi-Cal. I can't afford health care. I have medication that costs $50 a month, minimal. I can't afford to pay that $198 a month out of my $536 and live.

I have continuing physical and mental trauma and disabilities as a result of that. I can't afford to see a psychiatrist that I should be seeing that was helping me overcome some of these things, because I can't afford Medical.

I think that, particularly, anyone should get benefits they need, particularly anyone who is trying to, you know, become gainfully employed again and have to be totally retrained. And the fact that I can't receive either the medical help or the help that I need and look toward being somebody that should be working. I would like to do that. I was told by the Social Security Department, when I went for my reevaluation, that if I attempted to work, if I showed that I would even attempt to work, that I would lose my benefits.

My fear is, as Dan said, that right now, I can't afford Medi-Cal. What am I going to do then if I am unable to work, as I have been unable to work the five times I tried before? I would like to be able to be trained at a gainful employment where I know that I would have a chance to work and I would be given a decent period of time in which to prove that, and not to be completely cut off and then be out in the street later on.

Thank you.

Mr. STARK. Thank you very much.

STATEMENT OF SHEILA MARTINSEN ON BEHALF OF THE CALIFORNIA ALLIANCE FOR THE MENTALLY ILL

Ms. MARTINSEN. My name is Sheila Martinsen. I live at 3796 Oakes Drive in the city of Hayward.

I have been, for the last 6 years, the chairperson of the Families of the Mentally Ill of the Mental Health Association of Alameda County, which is a member of the California Alliance for Mentally Ill. It's an amalgamation of groups of families from all over the State of California, organized for advocacy for the mentally ill.

I also am past president and a founder of a rehabilitation program for the mentally ill in Hayward; namely, Eden Express.

The quotation stated here before about disability being apparent to anybody who will open his eyes and see is not true for the mentally ill. Their disability is not obvious to anyone who will open his eyes and see. And the record shows that the mentally ill constitute 11 percent of those who are disabled, but constitute 30 percent of those who have been discontinued on their benefits. Also, we know that 9 out of 10 times, discontinuation decisions have been overturned by the administrative court judges.

Oftentimes, I think, why families are so important to be listened to is that we have become probably the greatest advocacy group on the level of dealing with the bureaucracy. In having to go through this kind of thing, we know what's happening at the street level. I just wanted to let you know of a very recent personal experience I must mention: I am the mother, also, of a 27-year-old schizophrenic son, who has been hospitalized 17 times in the last 7 years and in and out of halfway houses, satellite programs, has lived in trucks, on the street, and various other kinds of places—I just wanted to tell you when his case came up, what happened.

This paper in my hand is the friendly envelope you get and it says, "Department of Human Services." That sounds very nice. And, yet, we look at it and wonder "what's going to happen now?" In our eyes, it's frightening. I pick this out of the mailbox and I feel the way the people in Russia must feel when the knock comes on the door at midnight. What is going to happen now?

So paranoid, we've become, that when this envelope arrived—and let me say, what the district office's lack of knowledge of the mentally ill is like—I received this in my mail at 5 o'clock at night on a Friday. The notice said that "You must tell us on Monday"—the only business day—that was May 2, "You must let us know prior to May 3 whether you can keep this appointment, or not."

It so happened that we were leaving on a trip. My son does not live at our house. He lives in another county. He uses our address so that there can be some stable place where his checks will come and information like this will come. So paranoid are we about the bureaucracy that I postponed the trip and sat down and wrote a two-page letter giving them his history, saying this is what is what and we will phone you from the road on Monday to make sure that nothing will go wrong. We called the office and said we cannot be back in the city of Hayward until May 23, and they said, "Fine, come in on the 24th." And we were to bring clinic numbers, all this kind of data, and were I not the kind of person I am—I happened to have lists of hospitalizations, discharge and so on—that kind of information would take weeks to accumulate. Oftentimes I don't know the name of the doctor who treated my son. I don't know who's at North County or South County Mental Health, this kind of thing. I don't know those things. My son certainly does not.

In our case, we got the notice. It was taken care of. We did go on the 24th, and the chap who waited on us had not even read the letter.

My point really is that there is no way you can even be sure these letters are going to be delivered to the person, when a patient is 3 weeks here, 4 weeks there, in various facilities. You can't depend upon the staff in homes and halfway houses and satellite houses to see that those letters get where they are supposed to go. Oftentimes, staff don't even know where those people are.

I have often walked into the satellite house where my son has lived—before we have gotten him into the hospital—and on the table will be letters to him from the county that say definitely, "Do Not Forward." There they will be, lying on the table for 3 and 4 weeks at a time with no attention paid to them. Something has to be done to make sure that the notice even arrives.

The notice, itself, seems terribly threatening, and it seems the language is designed to be threatening. Some of these people who see that envelope are immediately threatened, and say, "Here it is again. It's better I don't even pay any attention to it." I have seen letters like this in the wastepaper basket in my son's room when I have gone to pick him up.

Something needs to be done to make sure that the person does know, does receive the notice. Further, the person can be under such stress, under such mental condition, that they can't even read that stuff. None of us like to fill out forms. If we would once in a while say, "What is it like to be like that? What if it were me?" I find it very difficult to read forms. I don't know anybody who likes to read forms, fill in forms. Forms never really hit the spot, and you're expecting someone who may have just been discharged from the hospital, whose mind is concerned with the strange objects that are appearing before him, the paranoid feelings that everybody on the street is after him, with questions like "Where am I going to eat, what should I do?" And social security is expecting that they are going to sit down and look at that typewritten form, so totally threatening, so totally uncaring, and that the patient is going to say, "Oh, my, whatever happens, I'm going to get down there." We're talking about people like my boy who, if he's got an appointment in the morning, has five alarm clocks to make sure that he gets up, all of them a different number of feet from his bed.

In making a decision as to whether these people can work or not, the biggest problem is the misunderstanding of the illness. The person can, at this point, today, look very well, but tomorrow, next week, that may be all over, and they may have rapidly deteriorated. I think there is no appreciation for the loss of energy that comes with illnesses like schizophrenia, and I was going to say, as you, Mr. Stark, said, that with everyone else, with criminals we presume they are innocent. These people should be presumed to be ill.

To follow that analogy, when somebody comes into court, they are not only presumed innocent, they may even be a confessed murderer or charged with that, but when taken into court, they don't come in alone. As Dan said, in Alameda County, we do have the Advocates. But the Advocates, like every other mental health facility, deals with those who come in the door, but if you have all those people out on the street who do not know; and the lack of flow of information seems absolutely incredible. One group can be two blocks down the street from one another and not know that that's the place where someone who is talking to them should go to get help.

There should be advocacy supplied for people when they go for these reviews.

I think one of the things that really must be taken into consideration for the SSD people is about medicare which already discriminates against the mentally ill. Some thought should be put into what happens to medicare. It all ends up being taxpayers' money, and I know there is a lot of difference between which pot money comes out of, but when you take a person who, because he happens to have had gainful employment before he became ill, gets SSD, and then because of that, gets a share of cost with Medi-Cal of $231. What one must pay for board and care is $451, which leaves him a minus income of $100 a month. It means in practice that person is being denied community care. And if you talk about cutting them off SSD, that means you would also be cutting off even what medicare will do for that patient. It certainly also means, in practical terms, there is not going to be any Medi-Cal.

The cost, then: When my son was cut off Medi-Cal, it took about 3 weeks to bring him to a state needing a very expensive hospitalization at Stanford University, all brought on by this kind of stress.

I would say that if someone comes in and says, "Oh, I am working," that may be someone who has, in a fit of great energy, taken on a job of shingling a roof or something like that. He is not going to last on that job more than 10 days or 2 weeks. It's a very dangerous job and there are no benefits.

The other point is: to have a patient come in and sit down for an hour with someone and have that worker make a judgment about mental illness is absolutely ridiculous. A person may go a year without having been in the hospital, but one must look at the longitudinal history of that person from Day 1. If my son had gone in last year he would have said, "I haven't been in the hospital." But this year he can say, "This is my 17th hospitalization, my second one for this year." The longitudinal history is extremely important in mental illness.

I think there should be a less demanding notice, a less threatening notice, a clear notice, and make sure that the person is indeed notified. Families are paranoid, of course; we think that that is really the first sort. If you can make all those people who don't get to the notice and who are incapable of responding to the notice fall through the sieve, then social security has aced out a whole bunch of people already.

I want to underscore what a number of people have said: the need for very gradual withdrawal from social security support and face up to the problem of loss of medical benefits. We have these people at Eden Express. They feel they could work 20 hours a week. Some would like to go into jobs like retailing, where the practice now is to hire somebody at half time so that benefits don't have to be paid. But they say, "What will I do for medical benefits if I do that?"

I think the most important thing, perhaps, is information, getting information out, but don't assume that the people know what they are supposed to do, and there is no way that someone who has spent years and years being mentally ill has got some little notebook that says, "I was patient number so-and-so in Stanford this year and, patient number so-and-so at Good Sam last year, and Fairmont the year before." Yet, the young man we went to see at social security wanted addresses, and phone numbers, and the names of doctors So-and-So. No, not even a careful mother has that. Certainly my son does not.

Thank you.

Mr. **Stark**. Thank you.

Mr. Eastham.

STATEMENT OF GILFORD EASTHAM, DIRECTOR, GOVERNMENT AFFAIRS, CALIFORNIA ASSOCIATION FOR RETARDED CITIZENS, AND UNITED CEREBRAL PALSY SPASTIC CHILDREN FOUNDATION OF LOS ANGELES

Mr. **Eastham**. My name is Gilford Eastham. I am director of government affairs of the California Association for Retarded Citizens. That's a statewide voluntary organization. I am also speaking this morning on behalf of United Cerebral Palsy Spastic Children Foundation of Los Angeles.

I can start by abbreviating my testimony by concurring with what has come before. There is an awful lot that's already been said that needs to be reiterated at the hearing.

Thank you for the opportunity to be heard. I would like to specify concerns that have to do with developmentally disabled. It's a little bit different but, generally, the concerns are the same, and maybe shed some specific light.

We are in support of S. 1144 and very happy to be in support of H.R. 3074.

I will begin by reviewing some of the data from the Government Accounting Office, from their April 7 report of this year. The data indicates that as of August 1982, the Social Security Administration had reexamined about 300,000 individuals and terminated benefits for 135,000 individuals, about 44 percent of the cases. About 75,000 cases reviewed involved persons with mental impairments and 42 percent of them were terminated. Of the 31,700 terminations, about 13,000 requested a reconsideration. Between June 1981 and August 1982, only 1,400 of the mental disability reexamination cases had their decisions reviewed by administrative law judges.

At the reconsideration level, the DDS's, sustained the termination in 76 percent of the cases, at the ALJ level, 91 percent of the decisions were reversed and the claimants' benefits were reinstated.

I think that we can specifically review weaknesses of the system by looking at the GAO report on page 6, where it indicates that some of the specific weaknesses identified were, first, an overly restricted interpretation of the criteria to meet the Social Security Administration's medical listing resulting, principally, from narrow assessments of an individual's daily activities.

Second, an inadequate development and consideration of a person's residual function capacity and vocational characteristics. Third, inadequate development and use of existing medical evidence, resulting in an overreliance and misuse of consultative examinations and, fourth, insufficient psychiatric resources in most State departments.

Special problems in dealing with developmentally disabled, mentally retarded individuals are very basic. Generally, the forms and the procedures are not geared toward persons with mental retardations. There is general lack of understanding, general lack of the necessary patience to deal with persons with mental retardation and a general misunderstanding of the disability. This deals with the forms that must be filled out, the procedures that must be followed, the dates that must be followed, et cetera. Notices of terminations, procedures for appeals, and the specifics of benefits regulations. I have an example that was brought to my attention this morning, of an individual that was terminated benefits because they did not know better than to share their checking account with their brother. Because of that, they were unable to continue benefits.

In California, of course, the community care of these individuals is based upon receipt of SSI and so as we see, if their SSI is in jeopardy, we're talking about community placement that's in jeopardy and the State department of developmental services bases its initial basic rate of residential service at $451 a month, which is interesting, as that is, of course, the SSI level.

So, again, we're not just talking about general benefits, we're talking about community placement in many cases and that's the difference between community interaction. Integration of the community means training in some of these other principles that we hold very high, as opposed to institutional placement. That's, in some cases, the only alternative.

The final point I wanted to make is something that was brought up earlier and that was the information with regard to section 1619 (a) and (b), we find the social security offices are not prepared to inform individuals about the continuing benefits that are available under section A, the medical benefits under section B and we find this to be lacking and we would like to see some direction with regard to advocacy in that area.

Again, I want to thank you for the opportunity of speaking before you.

Mr. **Stark**. I want to just pose a question to the panel, at the risk of subjecting myself to the political ridicule in the answers, but one of the things that we keep hearing about are the cheats and, obviously, Greg Saunders, who testified earlier, would not be able to cheat.

But in the area of mental illness, has anybody witnessed anyone trying to cheat? I can see what a professional might call a close call, in terms of somebody's ability to survive in a situation like the work place but that's a professional judgment. What are we doing in a system that encourages people to make up out of whole cloth the idea that they have some mental disability and then go to the social security office, trying to con some well-meaning long-suffering bureaucrat into giving them $450 a month?

I find it difficult, and I know that my opponent would say, "Stark, you're the perfect person; you just walk in and they'll put you on disability if they take one look at you," but that answer is not what we're seeking right now.

Does anyone know any areas where people are abusing the system? What should we look for there? If I can go back and tell all my colleagues that we've done away with potential cheats, then I can say all the money we're spending is being spent well. That's what seems to get us into this problem. That's what I perceive these wholesale terminations are. That's like some other governments that just round up a whole bunch of people and put them in jail and quell rebellion that way. But who wants to give me the inside story on how people cheat?

Ms. MARTINSEN. I don't know of anybody who has cheated. "One Flew Over The Cuckoo's Nest," the chap decided to cheat to get out of jail and go into the mental institution. We know what happened to him.

Mr. STARK. We had some testimony in Minneapolis a couple of years ago, when we were hopping around the country, of somebody running a sheltered workshop and they were preparing sandwiches for a canteen service. If they could get their workers to state that they were mentally retarded, they could keep them on subminimum wage programs and, therefore, have cheap help to compete in the sandwich business. That was some entrepreneur, you know, working in our capitalistic society, figuring out how to rip off the system. However, the person said, "I don't want to do that because then I will be branded mentally ill the rest of my life; I'd rather not work."

Ms. MARTINSEN. We were joking about this the other day. I was with the director of mental health of this county and we were saying this is almost the classic of catch-22, just exactly what it's talking about, that if you can receive that notice and read it and do it, go on right straight down there and bring all those clinic numbers and go in, lots of these people, ipso facto, you are not crazy because you were pretty much together to be able to handle something like that.

Beyond humor, that if someone is willing to take on the stigma of mental illness, they are in for an awful, awful life and I really don't know anybody who has decided that that's the way to go. I often think, as we hear about welfare cheats and all that—and they are always assumed to be these people at the bottom, where you're saying about this other case—to my experience, they are usually up here somewhere, if they are doing the cheating, because that's where the money is. It isn't at $582 or $451 a month.

What I was going to say further, this great huge effort to look for them certainly must cause more, I should think.

It produces newspaper articles and talk show call-ins. I've been hearing it for 10 years and I just have a little trouble getting any of them to appear and I'll offer them the bag-over-their-head treatment, if they want it. But I have trouble finding them.

I appreciate the time of all of you. The staff may have some questions now or they may want to be in touch with you later for information.

Mr. JENSEN. Let me ask a question of Sheila and the others there, the representative payee system was partially to deal with mentally disabled. Now, I gather, Sheila, your son, you've had the checks go to him. Are you his representative payee?

Ms. MARTINSEN. No, this is all done on an informal basis.

Mr. JENSEN. So you've decided that the checks should go to him just for his own purpose.

Ms. MARTINSEN. He's not conservable.

Mr. STARK. Is that the standard in California? I mean, to do that, you have to——

Ms. **Martinsen**. Not to have a payee, no. You can't have a payee without being conserved. But my point is, in having it come to our house is because, otherwise, those checks would be forwarded here, there, back, where is he, because some of the placements don't last more than a month or two. That's the problem. I couldn't begin to tell you the addresses that he has had in the last 5 years.

Mr. **Eastham**. In California, one of the interesting aspects of it is the SSI checks, where mentally retarded folks that are in community placement goes directly, I believe, to the regional center, if not to the department of developmental services. So any increase, say, cost-of-living increase and so forth, is immediately assumed by the State. It is not passed on to the individual so in terms of representative payee, the State, either in its guise as regional center or as State department of developmental services would receive it.

Mr. **Jensen**. Some have suggested that there should be—in fact, there was a national report on the chronically mentally ill back in 1980, and recent recommendations coming out of some various State mental health organizations—that there be a different definition for mental disability under SSI than under disability insurance. That we're dealing here with a minimum standard concept, as compared to disability insurance, which is related to how much wages they've made in the past. Do you think that's workable or is it one alternative we deal with here, as we deal with the mentally disabled?

Mr. **Jordon**. I'd like to answer that. I really don't think you can separate the definition for disability, depending on whether a person has worked in the past, or not. You could take a very clear example from identical twins; one has worked and one hasn't and they both suffer mental impairment. It's just too difficult. I don't see how you can separate the issue, "Well, you have to be more disabled than your brother here because he did some work." I just don't see how you can separate that out as far as qualifications for being disabled.

I think right now there are—even some of the separations are now being changed in the program, such as if you're on SSI, you receive your CDI notice, you're being cut off, you get to go to the hearing level and with social security disability, you don't get to go to the hearing level. You have to go to the reconsideration first and then if you don't pass that, then go to the hearing level, there are other delays in there. So I think any time you try and separate out rules, regulations, safeguards in the program because of the fact that someone may have had the opportunity to work versus someone who has never had the opportunity or ability to work, you run into a lot more problems than solutions.

Mr. **Stark**. Thank you all very much.

Carolyn.

Ms. **Loft**. Our committee has been doing some investigative work, talking to DES and claims reps and trying to find out at all levels what the problems have been. One of the folks I talked to at the DDS office suggested that one of the problems that he sees most frequently, especially in the area of deinstitutionalization, where social workers are trying to make recommendations to put clients, recipients in halfway houses. They often write glowing reports that reflect the recipients doing very well and then the DDS examiner will get ahold of this report and say, "Gee, they're doing so well, they don't deserve benefits." He feels that this is a real catch-22 and asks that any legislation we consider, that we try to take care of this situation.

Do any of you have any suggestions for this or have you run into this same problem?

Ms. **Martinsen**. I'd like Dan to answer this, as well, but one of the problems with psychiatric evaluation in this kind of letter is the fact the doctor or person writing this talks in generalities, rather than in concrete terms, when there is a difficulty in measuring, but can the person do A, B, C; not that this person who might be this or might do that and the unpredictability of the courses of the serious mental illnesses is very difficult. And one of the problems you're talking about, of course, is the whole idea behind the treatment of the mentally ill in the community is some idea of transition, as if you've started here and you were absolutely going to go this way and out the door, as if you had a broken arm or broken leg and you go from cast to sling to whatever, and it simply isn't true.

So what may have seemed true in general terms in 1981, will not be true in 1982, or even from August 1982 to January 1983. That's one of the problems.

Mr. **Jordon**. I think another thing you have to look at is also the context of the question, where if you have someone, a treating professional, stating that a person is doing better, right away, to social security, that means, oh, wait, better improvement, no longer disabled.

You have to look at the context of that. I think a real good example I can give is on a daily activity questionnaire which clients are sent to fill out on how are they doing, when they are up for review.

I remember looking at one of the clients who was going to the appeal level and later reinstated benefits, and it stated, "Do you visit with friends?" He put, "Yes, I visit with about 10 to 15 friends, 5 days a week for about 6 hours a day." But what he didn't put in there was that was required day program he was going to. So if you look at the context of that, you would say, "Hey, he's in treatment." And if you read just the answers that the client put down, you would say, "Hey, this guy can socialize with friends, respond; therefore, he is no longer disabled." So you really have to look at that issue.

Ms. **Wright**. Another point I want to make because I fit in the category of both physically and mentally disabled, is from my accident, I had brain damage. But because I don't sound like pigeonholed brain—damaged people, I've had difficulty getting any kind of rehabilitation, any kind of treatment, difficulty in talking with other people having them think that I am disabled at all, unless I have a problem where I'm unable to walk because of bone disease.

Yes, I'm on crutches, obviously. But, otherwise, it isn't. But I do have that disability. It is so incredibly frustrating. I have a problem with memory and unless you're talking to me for some length of time or, you know, even 10 minutes, you may not see that. I've also been able to compensate somewhat, but I still have it. And it is very interruptive as far as going foward and doing a number of tasks and things like that.

I think the problem, as has been stated, is judgment is made without really having true evaluation.

Mr. **Stark**. Thank you all very much.

We will have a panel now consisting of Don Cote of the Alameda County vocational program for rehabilitation of the mentally retarded; Greg Lim, the director of resources for Independent Living of Sacramento; Mr. Robert Scott, director of Hayward Socialization Center.

Dr. Richard Singer, would you come up, too, please. It will give us all a little more time. The Social Security Administration people are on the other panel and we are all due at the San Francisco Airport at 1 o'clock. To get as much input here, if we can put you all together, it will probably help.

Mr. Cote, you may summarize your testimony and it will appear in its entirety in the record.

STATEMENT OF DON COTE, DIRECTOR, ALAMEDA COUNTY VOCATIONAL PROGRAM

Mr. **Cote**. Thank you for the opportunity to be here this morning.

Mr. **Stark**. I will also suggest that for the rest of the people who are interested in hearing, if you will speak into these microphones, it will be a little easier for people in the room to hear.

Mr. **Cote**. One correction: Our program serves the mentally ill, not mentally retarded.

I am the director of the Alameda County vocational program. It is the vocational rehabilitation program within the Alameda County mental health system. We do not do therapy. We are exclusively a vocational rehabilitation facility. So the mentally ill clients who come to our program are all people who have gotten to that particular point in their recovery when they are even able to consider going back to work and that's what our job is.

What I would like to do this morning, I would like to address a couple of things, specifically the trial work period, which is absolutely essential for our population. Also, I'd like to talk a little bit about the problems we have had with social security receiving feedback from us in terms of making it their determination as to whether someone is ready and able to go to work.

The problem of dealing with the vocational rehabilitation of the mentally ill is a very complex problem that takes an awful long time to deal with.

The primary problem our clients have is fear. We're dealing with people who may not appear to be ill but who have a tremendous amount of fear, who have been suffering from either low self-esteem or the opposite, grandiose notions of what they can do and, invariably, lack of self-confidence.

The process of interacting with these clients vocationally is a lengthy one, 1½ to 2 years, sometimes 4 or 5 years. And involves a tremendous amount of money. We have a work adjustment program where clients come in and are in that program for anywhere from 6 months to a year and a half, where we deal with issues, deal with authority figures and coming to work, being on time, et cetera.

We also have community work programs. Our clients are actually placed out in part-time jobs for 3 or 4 months. We pay minimum wage out of a grant we have. This is an attempt for the people to get used to the world of work.

Now, the problem that we have is with someone who's mentally ill, who is faced with a decision of, "Should I try going to work, or not? Should I really risk giving up these benefits to do that?"

When you consider that an integral part of the illness, itself, is fear and consider that we're dealing with people, some of whom have never worked a day in their life. And the whole thing of will they be able to handle that 5 days a week, that 40 hours a week, when you're dealing with someone who already is suffering from very low self-esteem and very little confidence, usually the answer is no.

In our experience in our program, if we did not have this trial work period of 3 to 9 months, most of our clients would not attempt going back to work. They would definitely decide the risk would be foolish for them to take. They really don't have enough evidence in their life of success to assume that they would succeed. They would conclude that they would not succeed, that they would fail because that pretty much is what their track record has been.

The problem that we have with the trial work period right now is it's considered a trial period from 3 to 9 months. In other words, clients, once someone goes to work, they can be reviewed after 3 months, to be determined if they are able to work.

They do not have the full 9 months guaranteed to do this. We've had some very tragic situations in our program who have gone to work and who have been evaluated in, say, only 3 or 4 months and determined able to work and have their disability denied and been rehospitalized and a return of mental illness with some just tragic results.

The thing that we're really very concerned about is that with someone who is mentally ill, gets to this very critical point in their life when they are considering going back to work, with the promise that they have 9 months to try this out and if it doesn't work, they figure they are still going to be able to maintain their benefits. If they are reviewed after 3, 4, or 5 months, they lose their benefits, they are going to make a permanent decision about themselves in terms of them in the world of work and that's usually the end of it.

We've had several cases of people where this has occurred and they have been rehospitalized and it's been impossible to talk them into any further vocational rehabilitation.

The other thing that I wanted to talk about was the problem we have providing input to the people down at social security who make the determination as to whether someone is able to return to work, the vocational counselor on my staff has a master's degree in vocational rehabilitation and has been working in the field for over 10 years and has been working in mental health for 6 years and he is an expert in terms of assessing people's ability to be ready to go to work. That's what he has his master's degree in and what we have tried to do is work very closely with social security in providing feedback in terms of where our clients are at. We have been told that there is no basis in the law for them to receive this feedback. That, in fact, their determination is predetermined by the legislation, itself, by the regulations and the regulations do not include feedback from vocational counselors.

I might guess that since we are nonmedical people that perhaps it would be considered nonmedical valuations and, therefore, nonvalid.

The obvious reason for continuing this trial work period is that, as I said earlier, very few, if any, of the people that we serve would consider going back to work if they had to risk benefits immediately. Consequently, the result is that these people remain on SSI forever, are not ever going to take that chance.

That's really all I have to say. I'd be happy to answer any questions.

Mr. **Stark**. Thank you, Don.

[The following was submitted for the record:]

STATEMENT OF JOHN DYER, COUNSELING SUPERVISOR, ALAMEDA COUNTY MENTAL HEALTH VOCATIONAL PROGRAM

Dear Congressman Stark: To introduce myself my name is John Dyer and I am the counselling supervisor of the Alameda County Mental Health Vocational Program. The program provides vocational rehabilitation and counselling services to emotionally disabled people of Alameda County. The purpose of the program is to assist the emotionally disabled person to develop the skills required for employment and to make the adjustments necessary to obtain and maintain successful employment. The program does not provide therapy nor attempt to treat the disabling condition. Rather, the program helps people to learn how to function appropriately in a work situation and how to cope with the demands of the job, so their emotional disability will not handicap them from employment.

Thank you for the opportunity to address some of the issues of Supplemental Security Income regulations. The focus of my comments is centered on the "Work Trial" components of the SSI regulations.

It is my understanding that the Work Trial component of the regulation is due to expire in December, 1983. Simply stated, it is my strong, strong opinion that to allow the Work Trial component of SSI to expire would have disastrous negative repercussions on the people who receive SSI benefits and on the Supplemental Security income system itself. The Work Trial component is a critical part of the process, in the SSI system, that enables people to deal with a disabling condition and eventually return to gainful, contributing employment. It is an integral step in a disabled person transition from a disability benefit recipient to an employed taxpayer.

I can best illustrate the need for Work Trial by describing how it is used in our Vocational Program. 95 percent of the people in the Vocational Program receive SSI benefits. By definition these people have severe, incapacitating disabilities which require extensive treatment, including hospitalization, and which prevent them from working. By the time the disabled person is referred to the Vocational Program, he has achieved notable progress in his treatment and is able to see some light in the long tunnel of recovery. Hopefully, the Vocational Program gives form and substance to his picture of himself as a capable, independently functioning member of the community. But this person is very definitely still recovering and not recovered. He does not know if he can work, if he can cope with the stresses, demands and requirements of the job. He is experimenting with his strength and testing his stamina and endurance. He is very frightened of a relapse and its consequences but he is also hoping for and striving towards overcoming his disability. Since SSI is his sole financial support, his sole means of survival, he is not willing to discard his means of survival on the unknown commodity of his recovery. He is at a transition point. Work Trial is the tool to test out his capability, the method to experiment with the reality of his hope. It gives him the means to take the risk of working and make the attempt to complete his recovery. Work Trial allows him a period of time to attempt to handle a job and complete his recovery without giving up his sole financial support. If Work Trial was not available, if he lost his benefits the day he tried to work, the disabled individual is not going to risk his survival by attempting employment. He will fight to retain his benefit rather than explore the possibility of working.

Without the Work Trial opportunity, the SSI regulations would foster and promote an increased dependence upon the SSI system, rather than assisting the disabled person to move towards independence. Instead of reducing the incentives and the methods for the disabled person to overcome his handicap, the SSI regulations should be geared towards promoting, encouraging and rewarding the risk of independence and self sufficiency. I cannot over emphasize the importance of the continuance of the Work Trial regulations. Rather than allowing the Work Trial regulations to expire in December, we should be exploring ways to expand them, to make them more useful and helpful to the disabled person.

Not only is Work Trial necessary for the disability recipient, it also results in an extremely positive benefit to the Supplemental Security Income system. If a disability recipient makes an attempt at employment because of the Work Trial provisions and is successful, he changes from a tax user to a tax payer. If he attempts to work because of the encouragement of Work Trial but he is unsuccessful, then SSI realizes some savings by at least being able to reduce his benefit allowance during the time the disability recipient made the work attempt. The only time that SSI is the loser is when the recipient is discouraged from making an attempt at working.

Hopefully, I have made my case for the importance of Work Trial provisions and the necessity of their continuance. Assuming so, I would like to make some comments and suggestions on improving the Work Trial provisions when they are extended. First of all, don't keep Work Trial a secret. Make sure every disability recipient knows about Work Trial, knows how it operates, knows how they can make use of Work Trial, knows the purpose and goals of Work Trial. In my working with disabled people, I am continually surprised by the disability recipients who have never heard of Work Trial. How can they make use of such a beneficial program if they are not aware it exists? And why don't they know about the Work Trial? Because the SSI system has not promoted it, has not fully and clearly communicated Work Trial to its benefit recipients. If the existence of Work Trial provisions was generally known, there would be more usage and with more people using Work Trial, there would be more people reaching success at work and not needing SSI benefits. In our program about 50 percent of the people who attempt work through Work Trial are successful. But about 85 percent of the people in the program are unaware of Work Trial and its advantage to them. People should come to this program saying "I want to get started on Work Trial", "Help me develop a plan for Work Trial" rather than learn about Work Trial from this program.

In connection with promoting Work Trial through the SSA offices, I would recommend that disability recipients automatically be placed in Work Trial status when they begin working. I have been told and the disabled people I work with have been told by SSA offices that they must request Work Trial status. Why? Is it necessary to keep it a secret? It should be an automatic step into Work Trial when a recipient takes the initiative to get off of benefits by working.

Another recommendation is to clarify how the length of Work Trial is determined. Why does one person get three months of Work Trial and another person get nine months of Work Trial? I assume SSA has reasons or guidelines in determining the length of Work Trial for various people but the recipient has no idea of these reasons. Again, is it a secret? In determining the length of Work Trial, set up a method for input into the determination process from other professionals working with the disability recipient. Establish a means for vocational counsellors and/or social workers to provide observations and recommendations on the amount of Work Trial necessary for the disabled person. Seek out more than just the medical data in making the determination. I have been told by SSA offices that my input as a vocational counselor is not sought and that there is no way to introduce it into the determination process. I have worked with recipients who have needed the full nine months of Work Trial to insure any chance of success but they were only allowed three months or four months or five months. Many of these people were unsuccessful and returned to full disability but I suspect the outcome would have been different if their Work Trial had been longer.

In closing, I again want to thank Congressman Stark for the opportunity to present my ideas. As a professional working with the vocational rehabilitation of disabled individuals, I have found the Work Trial provision of SSI a useful tool in people achieving success in employment after disability and in realizing a return to independence and self sufficiency. It would be a significant loss not to have Work Trial as an option in the rehabilitation process. I strongly encourage its continuance and its incorporation as a permanent part of the Supplemental Security Income program.

Mr. STARK. Greg Lim.

STATEMENT OF GREG LIM, LEGISLATIVE LIAISON, RESOURCES FOR INDEPENDENT LIVING, INC., SACRAMENTO, CALIF.

Mr. LIM. Thank you. I am not the director of Resources for Independent Living. She is shorter than I am. I am the legislative liason, advocate, vocational rehabilitation counselor, and instructor for the developmentally disabled adults at the Resources for Independent Living in Sacramento.

I will not reiterate what Greg Saunders, my counterpart, has testified on the history of Public Law 96–265, or the reasons brought about that were proposed improvements of the equity of the program and program administration and to remove disincentives to work and participation in rehabilitation plans.

I shall address the three areas impacted by 1619 (a) and (b), title XVI, IXX, and XX, respectively. Supplemental security income, medicaid, or more commonly known as Medi-Cal in California, and social services serves the basic survival need to those individuals with disabilities. Food, clothing, and housing are provided by the cash benefits from SSI. Health care, health-related items are provided by Medi-Cal. Title XX provides a variety of support services which are essential to the continuum of services. One should be cognizant that these programs are not limited to the maintenance of an individual's life but in combination provides the necessary support system to which an individual with a severe disability or mental impairment can actively pursue an occupational objective. Our present high level of services and advanced rehabilitation engineering opens up the once unattainable goal of employment to those deemed infeasible.

The concepts of disability, instituted with the term "disability" became an integral part of the act in 1954, has created the dilemma of work disincentives, such as Greg has previously stated. That supposition was disabled individuals cannot engage in employment.

Section 1614 of the act also states that disability can only exist if the individual is unable to engage in substantial gainful activity or SGA, which is a sustained earned income of $300. Therefore, disability status was ceased, due to the ability to demonstrate SGA, regardless of a severe physical and mental impairment.

There have been exceptional individuals who have quickly transitioned off the rolls into self-sufficiency. However, it is unrealistic to presume the same for the majority of individuals with severe physical and mental impairments.

Those disabled persons who were maintaining employment, must meet certain expenses, costs incurred which are common to all workers. For example, taxes, dues, uniforms. They must be met, in addition to required expenses to accommodate the individual's disability, health-maintenance-related items, attendant care, special transportation, et cetera. These combined expenses in maintaining employment and basic living needs may offset the advantage and incentive for working. Thus, the working disabled individual may actually have less real income available to meet their needs, due to attempting employment; 1979 statistics revealed that the average annual income for a single disabled person was $1,600 and $6,000 for the married disabled. These figures, not only include the earned income of the disabled person but also the contributions of earned income of others residing in the household.

Three-fifths of the disabled adults of working age are at or near poverty level. Of the 15 million disabled Americans, between the ages of 16 and 64, who are not institutionalized, more than 7.7 million are unemployed. Among the severely disabled, 9 out of 10 are not working. About 25 percent of all persons not in the labor force are disabled.

Your legislation in H.R. 3074 and H.R. 2354 have addressed the work-disincentive issues. Resources for Independent Living believe that these pieces of legislation are vital and must become law. Together, we can encourage and motivate employable SSI recipients toward socioeconomic independence.

I have also brought forth a case example. This case example is true and not a unique or extraordinary case but confronted by all SSI recipients. I will refer to this case example as client A, male, 32 years old, accountable income, title XVI, $451 a month. Nature of disability, infantile progressive spinal-muscular atrophy. He is a severely disabled quadraplegic. There is no evidence of residual functional capacity of lower body and his extremities. Present residual functional capacity of the upper body in its extremities are very minimal. A back brace must be worn at all times to provide the adequate support to operate his electric wheelchair.

Profile: Client A wishes to engage in competitive employment. He is intelligent and articulate. Potential employment exists at part-time and full-time positions with wages averaging $3.50 per hour, $606 per month, would be $7,274 in gross annual income. His medical expenses average $5,000 a year. His attendant care services, title XX, cost $560 a month or $6,720 annually. He also resides in subsidized housing, section 8 subsidized housing.

Client A desires to be totally self-sufficient if at all possible. He would like to have an opportunity to contribute something back to society and, ideally, that would be through employment. However, if he did not want to reside in subsidized housing and pay out of pocket medical expenses and attendant care, he would have to earn approximately $2,000 a month. It would not be financially feasible for client A to accept a part-time or full-time position at $3.50 per hour, only to be deemed SGA after his trial work period.

As a result, his medical coverage and social services would be jeopardized.

This is common throughout the Nation. I just have articulated this example to inform you that many people, because of the threat of losing benefits, will not go back to work, will not attempt SGA nor have the desire with social security hovering behind them, threatening to cut off essential survival services if they earn over $300 a month.

Thank you.

[The prepared statement follows:]

STATEMENT OF GREG LIM, M.S., LEGISLATIVE LIAISON, RESOURCES FOR INDEPENDENT LIVING, INC., SACRAMENTO, CALIF.

Resources for Independent Living, Inc. is one of 25 Independent Living Centers in California, whose expressed purpose as a private non-profit agency is to promote the socio-economic independence of disabled Sacramento residents.

On June 9, 1980, President Carter signed into law the Social Security Disability Amendments of 1980 (Public Law 96-265). This was the product of study and discussion by both the Administration and the Congress. Increased growth of beneficiaries in the Social Security disability insurance (DI) program brought attention to the structure and administration of the SSDI program. As a result, proposals were developed to improve the equity of the program and its administration, remove disincentives to work and participation in rehabilitation plans, and provide work incentives.

This testimony shall address three areas of the Social Security Act. Title XVI (Supplemental Security Income). Title XIX (Medicaid/Medi-Cal), and Title XX (Social Services).

Supplemental Security Income, Medicaid or commonly known as Medi-Cal in California, and Social Services serves a basic survival need to those individuals with disabilites. Food, clothing, and housing are provided by the cash benefits from SSI. Health care and health related items are provided by Medi-Cal. Title XX provides a variety of support services which are essential in the continuum of services.

One should be cognizant that these programs are not limited to the maintenance of an individual's life. But in combination, provides the necessary support systems in which an individual with a severe disability or mental impairment can actively pursue an occupational objective. Our present high level of services and advanced bio-medical rehabilitation engineering, opens up the once unattainable goal of employment to those deemed infeasible.

The concepts of disability, instituted when the term "disability" became an integral part of the Social Security Act in 1954, has created the dilemma of work disincentives. When the Supplemental Security Income program was implemented in 1974, its premise was based on an inaccurate and inappropriate concept of disability. The supposition that disabled individuals cannot engage in employment.

Section 1614 of the Social Security Act states that a disability can only exist if the individual is unable to engage in "substantial gainful activity" (SGA). Currently, SGA is determined by the level of work activity and the ability to sustain earned income at $300 per month. The ability to perform work activities is the basis for SGA determination. Therefore, disability status will cease due to the ability to demonstrate SGA regardless of a severe physical or mental impairment.

There have been exceptional individuals who have quickly transitioned from SSI status to self-support. However, it is unrealistic to presume the same for the majority of individuals with severe physical or mental impairments.

Those disabled persons who are maintaining employment must meet certain expenses. Costs that are incurred which are common to all workers, e.g., taxes, dues, etc., must be met, in addition to required expenses to accommodate the individual's disability (health maintenance related items, attendant care, transportation, etc.). These combined expenses in maintaining, employment and basic living needs may offset the advantage and "incentive" for working. Thus, the working disabled individual may actually have less real income available to meet their due needs to attempting employment.

1979 statistics revealed that the average annual income for a single disabled person was $1,600 and $6,000 for the married disabled.[1] These figures not only include the earned income of the disabled person, but also the contributions of others residing in the household. Three-fifths of the disabled adults of working age are at or near the poverty level. Of the 15 million disabled Americans between the ages of sixteen and sixty four, who are not institutionalized, more than 7.7 million are unemployed. Among the severely disabled, nine out of ten are not working. About 25 percent of all persons not in the labor force are disabled.[2]

Legislation which has been introduced, H.R. 3074 (Stark) and H.R. 2354 (Ford), addresses the work disincentives issues. Resources for Independent Living is in full support for these House Resolutions. We believe that these pieces of legislation are vital and must become law. Together we can encourage and motivate employable SSI recipients towards socio-economic independence.

Mr. STARK. Thank you very much.

Mr. Robert Scott.

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[1] Frank Bowe, "Rehabilitation America: Toward Independence For Disabled and Elderly People," Harper & Row, New York, 1980.

[2] Merrill Shanks & Howard E. Freeman, "Executive Summary For The California Disability Survey," Prepared for the California Department of Rehabilitation, Winter 1980.

STATEMENT OF ROBERT SCOTT, DIRECTOR, HAYWARD SOCIALIZATION PRE-VOCATION CENTER

Mr. Scott. There is one addition I would make. We now are the Hayward Socialization Pre-Vocation Center.

The primary function of this organization is to deal with the chronic mental patient with the intent to help them become more independent.

Our referral source out of this program is into several other alternatives, such as the Eden Express Restaurant and Don's program of the Sheltered Workshop.

The issue that I would like to address would be the contagious factor of the social security review. At the center, where we deal with the chronic patient, trying to work with them to become independent, and to help them develop the work skills that they need to compete in the open market, for one person to be reviewed becomes a threat to the totality. This is an effect that I don't think can be registered in terms of just out and out data. We have only had one person reviewed at the center during the past year. Yet, there were approximately 75 individuals affected.

Just to briefly summarize what occurred with that was that the individual that had to go before the review suffered a complete regression of her mental progress. But the total impact that we saw within the center, that during the time of her review, we had no success with any of our clients. We had a complete withdrawal of interest in our work projects and in our training program and it took approximately 4 months before we could begin to break through that problem and help the individuals begin to look at work as feasible alternatives for themselves.

I think I would like to end it with that, just to look at this additional information.

Mr. Stark. Thank you.

Dr. Crispino.

STATEMENT OF RICHARD CRISPINO, M.D., EXECUTIVE DIRECTOR, BONITA HOUSE, INC.

Dr. Crispino. I am the executive director of Bonita House. We serve the mentally disabled population.

I am going to limit my presentation today to my observations on the impact of the CDI on the mental health care system and the individuals served by SSI.

It's been my observation that this has been a cruel hoax as we're going on here and that's about this pass the buck. Pass the expense.

It seems the feds want to get out of paying for these expenses on the social security system, weeding people off the program, pushing them back to the States. The State of California is not increasing its funding for mental health services so they push the folks to the counties. The counties are not increasing the fundings because they are not there and mental health services are not being provided.

As this buck passing goes on, what happens is that people that we serve who could utilize the least restrictive care, the least costly care are in the process now of deteriorating because they are on the streets and then go into the hospital. The irony is that 1 day for an inpatient, say, at Highland Hospital is equivalent to 1 month on SSI.

When your office called me to speak today, I was asked to bring some recipients. No one appeared today. They are very scared, petrified to be here to testify. I think that's a statement within itself. We serve hundreds of clients and could not get one to come.

I do have some tales to tell. One client who is also working with Dan Jordon's office was approved for SSI 7 months ago and is yet to receive the first check.

We have other clients who have gone to programs like the one at Eden. In 3 months, they are up for reevaluation. When that word gets back into the community about a reevaluation after 3 months, it undermines the whole concept.

Mr. **Stark**. In your program at Bonita House, does the amount received from Medi-Cal and SSI cover your bare costs?

Mr. **Beard**. Without the SSI, you don't have enough funds. There are many people who need the services who are unable to get the services who, sadly enough, are on the streets today.

Dr. Singer, director of the mental health center in San Leandro.

STATEMENT OF RICHARD SINGER, M.D., DIRECTOR, EDEN COMMUNITY MENTAL HEALTH CENTER, SAN LEANDRO, CALIF.

Dr. **Singer**. Eden Community Mental Health Center is one of several mental health centers in Alameda County. The majority of our adult patients are considered to be severely mentally disabled and have long histories of serious mental illnesses and multiple hospitalizations and are considered to be at high risk of rehospitalization under the best of circumstances.

Our efforts are primarily aimed at maintaining these people and treating them in the community, minimizing this risk of hospitalization and utilizing whatever medical and social and economic resources are available to us.

SSI, of course, has been the primary resource available to these people to cover their basic needs of food and shelter. In the past 2 years, or so, we have noted clearly an increase in the termination of these benefits as well as an increase and greater frequency of denial in initial applications being filed. This, itself, has caused many problems for outpatients and their families.

But what's even more of a problem to everyone has been the incredible amount of effort and incredible length of time necessary to pursue the appeals process, once these denials come out. The denials appear to be quite arbitrary, in our opinion, with very little justification and connection to the actual client being reviewed, if anybody really took a long hard look and carefully evaluated that particular patient's situation.

When they are sent to medical consultants to review what has gone on, they have come back reporting that these reviews are brief and quite perfunctory.

In past years, the appeal process was fairly manageable because it took about 4 to 6 weeks and there were more legal and social assistance agencies available to help these people and there were also some funds available for temporary housing for these people at apartments or at halfway houses where many of these people reside. We were able to carry them for a period of time, for a short period of time, with expectation for reinstatement of these funds fairly high. It was a workable situation; not the best, but workable.

However, under the current situation, it's not workable because it doesn't take 4 to 6 weeks anymore but 4 to 6 months, in most cases, and there are cases that have taken up to a year, as you've heard.

One of the problems is that those already receiving benefits but who are denied continued benefits must apply for their appeal within 10 days in many cases, sometimes 15. That's really, as you've heard, very unworkable. These people cannot react in that period of time. Even a longer period of time is very difficult, mostly because of the severity of their mental disability, but also because of the lack of information that comes to them and to us.

So what happens is that they either lose their papers or they deny the whole thing and they just don't tell anybody for awhile—they simply become overwhelmed. They don't have the perseverance to really follow through on all this, even with some help. They just give up.

Then when they are cut off from that basic food and shelter money, what happens is they get discharged from their board-and-care homes and halfway houses because those facilities just cannot carry them as they have in the past.

People go back to families. Sometimes it's workable. Many times it's not workable. There are many stresses within those family structures, which create situations not conducive to them living there in the first place. There are all kinds of other reasons why family situations may not be the best place and they end up living in the streets.

What happens is the stress levels go up, their symptoms exacerbate and they wind up using the very much more expensive hospital emergency rooms and that also seems counterproductive. There are some cases that have wound up in the criminal justice system, as well.

At outpatient services, what we find is that more time has been necessary to devote to helping these people through the maze of the appeals process. The result is that we have less time to spend on providing services to the rest of the community who are requesting mental health services for other reasons. So it's not just the SSI recipients that are being affected by this. It's the rest of the community, as well, because the effect just snowballs right down the line.

Mr. STARK. In treatment and support systems that you all represent in different facets, is there some way that we could reverse this? Is there some step along the way where we change the responsibility and say, It becomes your duty, either professionally or in the legal sense, to tell us—"us" being the Federal Government or Social Security—when the person is no longer disabled? The fear always is somebody's going to cheat, so I guess I have to say is there a process where we would be fairly sure that some of you aren't feathering your own nests by keeping more people in your programs than ought to be there or somebody's got several relatives that they are putting on the rolls to eat better? Does anybody have any ideas?

Mr. **Scott**. I don't know if I have any answer on this or not, but certainly one factor that I would like to see in terms of working with people to move toward independence is to take on that responsibility, not only as a professional working with them, but to pass that responsibility on to the client, themselves. That progress can occur with you and when that occurs, the responsibility or the responsible action is to inform SSI of changes that have occurred and it seems like since we're talking about a long duration of treatment and several years of work effort before a person is ready to be cut loose from social security, it seems like that aids in the total concept of an individual becoming independent and responsible.

It would seem to me like it would be very feasible for SSI to allow us to work with them in making that determination.

Mr. **Stark**. It's symmetrical. If you make a lot of money, we rely on you to voluntarily tell us about it when you fill out your income tax form. There are a few people who fudge a little bit in that area, too. But when they forget and move the decimal point a few places, it really impacts our Federal deficit.

But, seriously, there is a symmetry to that.

Mr. **Scott**. I think along with that is the fact that service agencies all through the line are highly scrutinized. We are constantly being accountable for what we're doing and what we've served.

Mr. **Stark**. Well, I guess that's what I was getting at. But I just wonder if there isn't in California, where we have a good record of administering these programs, some simpler way where somebody can now certify that a person is disabled and meets that need for me.

I think Allen Jensen has a comment or question.

Mr. **Jensen**. There was the original concept that's still in the SSI and disability insurance program of a plan for self-support. I think the original idea of that was more the physically disabled that, you know, after so much time that you have a certain kind of disability, certain kind of training and you will have certain kind of rehabilitations of, say, a part of you that's been injured, eventually then that you will be able to work back into full-time employment.

Now, I assume in your work that you some way have some kind of a plan of services for people that come into your system. Is it possible that that could be made a part of the record? This is a progressive thing, this is what we have in mind as far as long run, realizing, measuring progress toward self-sufficiency, self-support, or some degree of self-support. It's very difficult in the mental disability area. Is that feasible?

Mr. **Lim**. You've mentioned a point I think is inherent, that cuts across the board and that's knowledge of systems. Not only were district offices and branch offices of social security unaware of 1619 (a) and (b) or at least if they were aware, they did not make that information known to the claims representative. In addition to the State departments of rehabilitation throughout the Nation, it should be incumbent upon them to know those regulations so that they can compose appropriate rehab plans and your plan for achieving self-support, which was enacted in 1974. It is another one of those areas that was not disseminated among the DO's and BO's and as a result, another vehicle which is viable to mainstream disabled persons with mental or physical impairments into the competitive labor force is underutilized. So what we have here is a continuing services provided at local levels unknown to the State and Federal agencies on implementation—much less an implementation, an assessment of feasibility of plans to remove SSI and DI recipients off the rolls.

So it's been passed on to local grassroots agencies who have become knowledgeable in the system, who have worked the system to their advantage since that's the name of the game and what we have are systems at the local level, doing the best they can innundated with reconsiderations and hearings, legal centers throughout California cannot handle this load, they are referring now to private attorneys and there is more to it than just employability. There are variables involved that sustain and maintain employment known as daily living skills which one must become aware of and be able to utilize as independent living skills to maintain and support employment above and beyond SGA levels.

Mr. **Jensen**. Mr. Cote, you mentioned the idea of the need for vocational experts to be involved and one of the things that's in Mr. Stark's bill was that when they redo the criteria for mental disability, that a vocational expert should be of that panel.

Now, I think that there is also a provision in that bill that provides that, you know, there be requirements for evaluation by Congress and psychologists. I think what you're saying also is that perhaps that should be further changed to build in the whole matter of the vocational expert being involved in action determination, not just the matter of developing the criteria.

Mr. **Cote**. I am by profession a psychiatric social worker and function as a therapist prior to going into vocational rehabilitation. And the whole thing of vocational rehabilitation and job readiness is not part of a psychiatrist or psychologist or social worker's training. It is a separate field. I think the determination of job readiness is very difficult training and requires an expert and I think that absolutely, as I mentioned earlier with respect to trial work and especially with the mentally ill. They appear functional. You know, and the task of assessing the job readiness requires an expert, requires certain types of testimony.

Mr. **Jensen**. Let me ask you directly on the question of this, you know, plan for self-support and other than, you know, 1619, do you have an effective plan as far as how long you think it will take for people that come in to your program and a way of laying on ahead of time how you're going to assess whether they are going to be employable at various levels?

Mr. **Cote**. We have plans that are averages. We know on the average, how long our clients are going to be in particular phases of our program. And the thing is, however, we serve a variety of different types of people with different severity of mental illness and we do have some who are able to transition in and out of programs in relatively short periods of time and we have some who have been with us 5 years. Most of them do tend to average out at about 18 months. So my answer is, yes, on an average we do have a plan that involves various stages of development. Initially, it's a 1-month evaluation program, followed by a 6- to 9-month adjustment program, followed by a 2-month counseling program, geared toward community work try-out, followed by a 3- to 4-month community work/trial job in the community, followed by free placement services and eventually placement.

Dr. SINGER. I would just like to add to that to say that that plan that does get carried out in the vocational program is one that's cooperatively worked on between the client, vocational counselor, and the therapist at the outpatient center. Everybody knows or should know what the plan is and how it's progressing. If we added to that, then the element of the reviewers in the social security office, being a part of the cooperative effort, it would make a whole lot more sense and be much more feasible to move along with the plan. If everyone does it together, ideally it will work better.

Mr. COTE. I would just like to add one other thing and that is the State department of rehabilitation is also involved with all of our clients and the Federal Government already presumes that the department of rehabilitation has the ability to evaluate people with respect to job readiness and since they are working with us, that's one possibility in terms of having to say to a third party, who will make that determination.

Mr. LIM. I would also like to support the contention that a vocational expert is absolutely necessary on evaluation for it is not within the jurisdiction of the consulting examiner to make the assumption that a person is work ready, job ready and to use the transferability of work skills as a tool as the Department of Labor has put out on analysis of jobs. There are 122 transferable work skills and I do not believe that consulting examiners are briefed in the 122 variables that are used to assess work or trade functions.

Mr. STARK. I would like to thank all of you for taking the time to come here this morning and help us. Hopefully, we can provide some small forum. I wish we could talk about a lot of funds which would help, but I'm afraid that is not on this year's agenda.

Thank you all very much.

We will now have Gayla Reiter, president of the San Francisco area of the American Federation of Government Employees and the Council of Social Security Field Offices. She is accompanied by John Kelly, East Oakland Social Security Office; Howard Egerman of the East Oakland Social Security Office; and Jan Arnold of the West Oakland Social Security Office.

Ms. Reiter, does everybody have testimony or do you want to present testimony or what do you have?

Ms. REITER. Everyone prepared a statement and it depends on time.

Mr. STARK. If you have prepared statements, if you could summarize those, we will put the full statement in the record.

STATEMENT OF GAYLA REITER, PRESIDENT, REGIONAL COUNCIL 1147, PRESIDENT, LOCAL 3172 AND EXECUTIVE VICE PRESIDENT OF COUNCIL 220, AMERICAN FEDERATION OF GOVERNMENT EMPLOYEES, NATIONAL COUNCIL OF SOCIAL SECURITY FIELD OFFICES

Ms. REITER. Unfortunately, because of my travel schedule, I didn't find out about this until Friday and I had a workshop all weekend so my comments are in handwriting so I will just go ahead and present those and then we will proceed from there.

Mr. **Stark**. Super.

Ms. **Reiter**. My name is Gayla Reiter and I am an elected union officer in the American Federation of Government Employees. I hold offices in our local and regional structure and I'm the first vice president of our national union. I am also a claims authorizer with the Social Security Administration and have worked in a variety of positions for SSA since graduating from college in 1967.

Our union represents over 35,000 social security employees in field offices in over 1,500 field offices throughout the United States.

I come before you today to speak in favor of the legislation proposed by Pete Stark in H.R. 3074, and to encourage a broader review of social security CDI and disability policies and regulations.

Testimony by the GAO, the Director of Human Resources Division and various State and Federal officials before various Senate subcommittees have summarized major changes in the criteria for social security disability benefit approval.

Today's regulations are much more stringent than they have been at any time in the past. The vocational grid that was implemented in 1979, made it very difficult to consider any nonmedical factor in determining an individual's disability and this is especially true for any individual that's under the age of 49.

Individuals with severe impairments that are under age 49 cannot rely on any lack of training, skills, or education to be considered unless they are virtually illiterate. The criteria for disability listings has undergone major revisions. Formerly, a significant number of beneficiaries were approved through what was called a combination of impairment provisions.

For instance, in 1975, over 45 percent of all the awards were based on equaling the medical listing. That is, the impairment, itself, was not specifically met but it was considered equal in severity to the listings when you combine the various impairments that a person has.

In 1981, less than 9 percent of all awards were based on equaling the listings. That is, using a combination of impairments to entitle an applicant. Now employment must meet the listing in at least one category or he can't be approved. For example, oftentimes claimants have heart disease, arthritis, and depression or some form of mental illness. The State agency must find that at least one of these illnesses is so severe as to meet the listing independently. Disability examiners have told us that many beneficiaries allowed in the past with multiple impairments are now being terminated under the periodic review, the CDI, because their impairments are being looked at independently, rather than measuring the total impact of their various impairments.

We're losing perspective. In addition to almost eliminating the combination of impairment criteria, social security has changed criteria for CDI, instructing the State agencies to make the determinations, to adjudicate these reviews in the same manner as they would initial claims, gathering only current evidence, usually within the last 2 or 3 months.

This often results in inadequate information, especially disadvantageous to individuals with mental impairments. Many individuals who have emotional illnesses, stabilize when on a regular program of medication and support. But once they are subjected to stress, such as working or going to disability interviews, have a reoccurrence of a psychotic or depressive episode.

The costs both in agency personnel and administrative proceedings, as well as human suffering, is high and has resulted in several suicides. The cost is great.

The San Francisco Chronicle recently ran a report of 11 people who had died, yet were denied social security disability payments. SSA's determination has been that each of these were well enough to work.

I'm aware personally of a CDI, where a State agency made a determination that the individual was not disabled retroactively and asked for repayment of the resulting large overpayment. The man filed a reconsideration and died while his case was being reconsidered. He died of the same condition that he had originally been approved for. Despite the fact that the State agency knew of his death and had his death certificate, which listed the cause of death, his claim was still denied. Even death wasn't enough to consider his condition disabling.

Approximately 45 to 60 percent of all of the individuals being reexamined for disability are not approved for continuation of their benefits. Now, that's staggering. Over 50 percent of the people that are being reexamined, even though some of these people have drawn benefits for 9, 10, 15 years, suddenly our administration is saying, "No, you are not disabled any longer."

This, in spite of the fact that these people, the majority of them, show no medical improvement and this has been documented by studies that have been done by social security. These periodic reexams have been greatly stepped up. The numbers are vastly exceeding the once every 3 years that was mandated by section 311 of Public Law 96-265. They have been stepped up to the point where such huge backlogs exist in California that a moratorium on processing these claims has recently been declared. Many social security offices have such huge backlogs of CID files they've run out of filing cabinets and have boxes stacked up containing the backlogs—backlogs neither social security or State agencies can handle with current staffing. Additionally, these reexams subject people who have been drawing social security, often for several years, to a completely new decision, using new standards. Many advocacy groups have challenged this premise on the grounds of res judicata and administrative finality.

A recent suit in the State of Washington, *Evergreen Medical Group* v. *Sweiker,* resulted in a court of appeals decision, which would prohibit termination of benefits unless the medical improvement could be shown.

There are various other class action suits that are pending throughout the United States that make this same claim. The pressure has come down from the top and has filtered down to we in the district offices. President Reagan has announced his determination to weed out the so-called undeserving from the disability rolls. Pressure has been brought to bear on social security employees and State agencies, to disallow claims and to get individuals off the rolls. We're being pressured to comply, get the numbers down, forget the human cost.

The Office of Hearings and Appeals has also been subjected to other reviews. Administrative law judges with too high of a reversal rate—that is, the reconsideration has been denied and the ALJ approved the disability after the hearing—are being disciplined. They are being threatened with termination if they don't lower their reversal rate.

We've been told that even if an ALJ reverses the denial and does approve a disability; these claims are automatically coded. They are programed on computers to come up for an automatic CDI within 9 to 12 months when they will again be terminated. So, even if these people have gone through the arduous process—and it often takes 3 or 4 years to get approved in the first place—they are going to have to go through the whole mess again in 9 months.

You have to think about what this is costing—costing in terms of money that we spend on personnel to process all of this paperwork and cost in terms of human suffering and the emotional turmoil for people to go through this.

This pressure, coupled with a depressed economy and high unemployment, leads to an explosive situation. Certainly, the disabled and, more particularly, those who have been on disability for years, are not competitive in a job market where even highly skilled and recently employed can't find work.

When people's disability benefits are cut, so are their medical and medication coverages, with often no resources often available at the State or local level to cover this loss.

This is especially true in the areas outside of California. There are individuals with obvious medical problems who will suddenly find themselves with both no income and no access to medical treatment. This mindless pressure to reduce the numbers on the disability rolls does not consider the human cost to our society, nor do these policies when taken as a whole, result in any dollar savings to the Government.

We as employees of Social Security are tremendously concerned with these issues and would welcome a closer look at our Nation's priorities. My colleagues who are interviewing claimants daily and are confronted with the heart-rending cost of these policies will now provide more specific examples.

Mr. **Stark**. Thank you, Ms. Reiter.

The next person on the list is John Kelly. I've read your statement and you might want to summarize some of it for us and we will get back to some questions.

STATEMENT OF JOHN KELLY, AMERICAN FEDERATION OF GOVERNMENT EMPLOYEES

Mr. **Kelly**. I've worked as a claims representative for the Social Security Administration since 1978, and throughout that 5-year period, my duties have included conducting continuing disability examinations and processing the appeals of the beneficiaries whose checks have been stopped.

The first point that I've mentioned in my statement was what I consider is an absurd limit for substantial gainful activity of only $300 a month. The minimum wage is $3.35 so this means that a person who is working at minimum wage only 23 hours a week would be considered to be doing substantial gainful activity and would have to have his benefits terminated. This means that anyone virtually, who returns to work is, after 9 months, going to have his benefits terminated because it's practically impossible to find a job, even a part-time job, where you would not earn $300 a month.

Something I wanted to point out in response to earlier testimony is that people who return to work are now automatically medically reexamined so that it's possible for a person to lose his benefits through the medical reexam and then be precluded from having the incentives that are provided under a 1619 (a) and (b). Those only apply to people who lose their benefits from substantial gainful activity and medical reexam prior to that, at the end of the 9 months' trial work period, would cut somebody off from those work incentives.

Unfortunately, the people who return to work are becoming a smaller fraction of the total number of people who are losing their benefits. The majority of people who lose their benefits are now people who are subject to these periodic reviews or automatic reexaminations and these people have none of the incentives or none of the support that is allowed under 1619 (a) and (b) of having medicare and medicaid continued after they lose their benefits. They automatically lose their entitlement to health care, which they depend on to avoid psychological or fiscal crises.

Something that I find very disturbing is the fact that all of the administrative law judge decisions are automatically programed to be reviewed within 1 year of the hearing and due to processing delays, this means that people who have only received checks for a few months are reexamined within only a matter of months and there is a very high reversal rate on those. I think it's an attack on the integrity of the administrative law judges. They tried to impose a quota, but the judges successfully had the quota removed.

An alternate limit is to just reverse all the decisions within 1 year. I'd like to end by saying that I hope that Congress is going to take action to reign in the Social Security Administration because I think through the CDI process, as well as the way the agency has processed overpayments, it has demonstrated that only through close public and congressional scrutiny are we going to assure that there is a humane and just implementation of the law.

If anybody has any questions on the plans for self-support, I think I am fairly knowledgeable.

[The prepared statement follows:]

STATEMENT OF JOHN KELLY, EAST OAKLAND, CALIF.

My name is John Kelly. I am testifying today as a representative of the American Federation of Government Employees. I have worked as a claims representative for the Social Security Administration since April 1978. Throughout that 5 year period my job duties have included conducting continuing disability investigations and processing the appeals of beneficiaries whose checks have been stopped.

Social Security employees have always had the difficult and often distasteful task of deciding whether beneficiaries who work can still be considered disabled. In general, a person who has worked for 9 months, not necessarily 9 consecutive months, and who in any subsequent month grosses more than $300 must be found to have recovered from his disability and must be removed from the disability rolls. To maintain that gross monthly earnings of $300 proves a person has regained the ability to support himself is absurd. Minimum wage in $3.35 per hour. A beneficiary

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working only 23 hours a week at minimum wage is performing what we call substantial gainful activity and can no longer be considered disabled. To give you a real life example, of how absurdly low this limit is, I had to terminate the benefits of a part-time school yard supervisor, even though this woman suffered from a severe disability. Several months after her termination she came in to reapply. Her condition had worsened and she was paralyzed. Clearly she had not regained the ability to support herself. Unless the earnings limit is raised everyone who returns to work will be found to have recovered and legitimately disabled people will continue to lose their benefits.

The people who lose their benefits after returning to work are becoming a smaller and smaller portion of the total number of beneficiaries whose benefits are terminated. Most people are now losing their benefits as the result of medical reexaminations which allegedly show the beneficiaries have recovered. In the 1980 amendments Congress offered a helping hand to the working beneficiary by mandating continuing medicare and medicaid coverage for a year after checks are stopped. The person who loses his benefits after a medical re-exam loses his health coverage immediately. This is terrifying for the majority of people who, the agency's decision notwithstanding, depend on their medicines and regular doctors visits to avoid physical and psychological crises. I do not find it at all suprising that, faced with the loss of their only source of income and loss of their health benefits, some beneficiaries have committed suicide. These are people who have been out of the workforce for years, people who before applying for benefits confronted their illnesses and had to admit that they could not work. With few exceptions these people have noticed no improvement in their conditions. Over the past 5 years I have interviewed many thousands of beneficiaries. Not even a half a dozen of them had ever received any help from vocational rehabilitation; 2 or 3 of that half dozen had been told they could not be rehabilitated. I must conclude, and I think you must agree, that the Social Security Administration is so zealous about terminating benefits because policymakers see the beneficiary as just another statistic, another work unit to be counted, not as a person struggling to cope with a serious illness or injury.

I am very disturbed because it seems that the continuing disability investigation process is being used to undermine the integrity of the administrative law judges. Perhaps you read about the judges who successfully sued the Administration because they were being disciplined for allowing too many cases. Virtually all of those allowances are being reexamined within a year after the hearing. Due to processing delays that means the cases are reviewed within a matter of months after the first check is issued. Almost all of these beneficiaries are having their benefits terminated. In theory, the administration has failed to limit the number of cases the judges allow, in practice the CDI process is an even more effective limit than a quota.

In the majority of cases the disability reviewers and agency doctors are not sending the beneficiaries to specialists in occupational medicine for an evaluation of the person's ability to return to work. Instead, the reviewer simply gathers records from the doctors and hospitals which have treated the beneficiary. The treating physicians are not asked to evaluate the patient's readiness to return to work. The physicians have not done tests to see how long the patient would be able to stand or how much he could lift. Frequently there are several treatment sources, each treating a different ailment or set of symptoms. The agency is simply not basing its decisions on the medical evidence necessary to decide if a person is able to return to work. As a result, people are losing their benefits or being forced to endure the ordeal of an appeal when they have not recovered from their illnesses or injuries.

I hope that Congress will take swift action to rein in the Social Security Administration. Through its handling of continuing disability investigations and its handling of overpayment collections, the Administration has proven that close Congressional and public oversight is necessary to assure just and humane implementation of the law.

Mr. **Stark**. OK., let's let your colleagues summarize their statements and we will come back to the whole panel.

Mr. Egerman.

STATEMENT OF HOWARD EGERMAN, AMERICAN FEDERATION OF GOVERNMENT EMPLOYEES

Mr. **Egerman**. My name is Howard Egerman, and I've been a claims rep and worked in the Oakland district for around 10 years.

In terms of my testimony, I primarily emphasize the interview slip and the reason why I emphasize the interview slip which we use in our office is that it is a device which translates social security legislation into actual living, breathing people; in other words, people who are affected by social security legislation coming to our office and when they come into our office their names are written out on this slip. We, as interviewers, call them for an interview.

One of the problems, which I list in my testimony, however, is that the CDI's are just one portion of the number of people that we interview. What has happened in the past, when we've had amendment changes, is that we've gotten increases in staffing, such as the medicare and SSI. But the 1980 amendments, which require a CDI, usually under 3 years, have not resulted in a large number of new people in the interviewing room to interview the claimants. They've resulted in a large number of people in the waiting room.

Mr. **Stark**. Do we make the waiting rooms bigger?

Mr. **Egerman**. More people waiting to be interviewed by fewer interviewers is what's really happened.

As for the CDI interview itself we normally have to complete it except for certain limited situations, which I listed as apparent or evident curtailment. The CDI process itself also takes a number of hours and this is on top of the amount of time that claimants have spent in our office waiting to be seen and also possible innumerable hours getting ready to come to the interview and, as some of the other people have testified, have mentioned their anxiety about coming into the office.

Then I went into the fact that one of my job duties as a CR is to carry out other duties as assigned and, in terms of recommending CDI policy changes, what I would like to suggest is that in terms of training, that we be trained about individual disabilities. Right now, we are primarily trained about the law. We're not trained exactly about particular disabilities, although our manager recently had us have two nursing students tell us about mental illness and alcoholism, and that was very helpful.

Also, that there be a job description for disability specialists or CDI specialists, who can handle all these interviews and develop expertise. One of the problems I am sure you must have received, Congressman, is that a lot of people are filing for retirement benefits or coming in for all their items and my complaint about the number of people and how long it takes them to be seen. If there are people only seeing disability people, people filing retirement claims probably can be seen faster. In addition, I think training for people who are ceased should increase. People who are ceased often ask me, "What do I do now?" Our cessation letters simply tell them that they can work because they are not provided with any training about how to fill out a résumé, how to prepare for a job interview, and how to get training for a new type of work when the economy has changed the type of job they used to do.

When I got out of the service as an able-bodied veteran, I had a hard time adjusting to civilian life but I had at least a VA and unemployment that could help me. Somebody who's going off disability is not as lucky so a job training program providing continuing payments, as long as the ceased person is enrolled, will certainly help them out because, as I understand it, the goal of the process is to help people back to work, not to shift them from one insurance program to another program, such as from social security and SSI to general assistance or the AFDC.

As an employee, I'm also aware of that fact that these proposals require money and the emphasis on lowered expenditures. But the people that this interview slip represents cannot be measured in pure dollars and cents.

Along with my colleagues, Congressman, I look forward to hearing about the proposals which you and the rest of the Members of Congress come up with. The interview slips that I've seen over my career in social security have taught me a lot about life. One thing I've learned—that I know that everyone here realizes—is that a disability is truly an equal opportunity "unemployer." It can happen to each of us.

Thank you.

[The prepared statement follows:]

STATEMENT OF HOWARD EGERMAN

My name is Howard Egerman. I am a claims representative at the East Oakland Social Security office, and am also a union representative there. I've been a Federal employee for 10 years.

This is an interview slip. Employees in my office use it to call claimants to our desks; in effect, putting Social Security legislation into practice. Yet while the claimants we see often view us as the govern the pronoun "you" often being used, we have little control over Social Security law.

The reason we are calling people into our office for CDI interviews and the state agency is increasingly removing them from the rolls is the 1980 amendments, approved by Congress and the President. It is not that we employees have less compassion for our claimants today than we did yesterday. Of course, we understand that policy makers often use sheer numbers to draft their policy decisions, but our interview slips translate these numbers into actual people, who let us know how legislation affects them.

One problem for us, however, [illegible] at this interview slip has spaces for many things besides CDI interviews. [illegible]uing disability recipients must wait in our waiting rooms on a first-com[illegible] basis with everyone else to be called. Furthermore, we employees specialize [illegible] particular programs, Social Security or SSI. There are no CDI or disabili[illegible]sts per se. And while CDIs have brought more people into the waiting roo[illegible]ve not brought more interviewers in them to service these people. In [illegible]ployees in our district must work several Saturdays a month in ord[illegible]plete their jobs and fulfill interviewing requirements. In addition, we must require CDI claimants to come into the office since an extremely limited travel budget forbids us to send out employees to claimant's homes in most situations.

As for the CDI interview itself, we must complete them except in certain cases known as apparent or evident curtailments. Evident curtailment refers to a person who has amputation of a leg at the hip, amputation of a limb, arm, hand, leg, foot age 55 or older, amputation of 2 limbs, an acute event such as a heart attack or psychiatric disturbance in our office or on the way to the office and a life threatening situation in which presence in the office might result in death.

Apparent curtailment refers to hospitalization at interview time or some other purpose. We are instructed not to curtail CDI development if a person threatens suicide or homicide but to consider this threat along with other evidence. And our regional office reviews all curtailment decisions.

The interview process itself can take several hours after a claimant has already waited for a while in our office.

Earlier I mentioned that my job is to carry out policy, not make it. However, "other duties as assigned" is also a part of job description and if I were to be assigned a duty of recommending CDI policy changes, I would suggest the following.

1. Training. Interviewers should be trained about individual disabilities, not just the law.

2. A specific job for disability specialist or CDI specialist should be established. Disabled people would get better and faster service and individuals filing for retirement or survivor or aged claims would also benefit by having to wait less time.
3. A policy of appointments for claimants previously determined disabled.
4. Travel funds earmarked so that claimants would be able to be seen at home.
5. Greater office leeway in curtailment of CDIs.
6. Training for people ceased. Individuals ceased often ask me "what do I do now." Cessation letters simply tell claimants they can work, they are provided with no training about resume completion, preparation for job interviews and get no training for new types of work.

As an able bodied veteran I had a difficult time adjusting to civilian life before I became acquainted with these interview slips. But I had the resources of the VA and unemployment to tide me over. Our ceased claimants are not as lucky. A job training program providing continued payments as long as a ceased claimant is enrolled would certainly help matters. As most employees understand it, the goal of CDI is to put people back to work, not to shift from one need or insurance program to another program such as general assistance or AFDC.

I realize that such proposals require money and am well aware of the current emphasis on lower expenditures. But the people this interview slip represents cannot be measured in dollars and cents, no price tag has yet been placed on human life, the issue which CDI represents.

I look forward Congressman to hearing about your proposals. I can assure you that my colleagues and myself are ready to enforce whatever proposals you enact. The interview slips I've seen over my career in Social Security have caused me to talk to many people who have taught me much about life. One thing that I've learned and I hope everyone here and your colleagues will never forget is that a disability is truly an equal opportunity unemployer, it cannot happen to each of us.

Mr. **Stark**. Thank you very much.

Jan Arnold from the West Oakland social security office.

STATEMENT OF JANET ARNOLD, AMERICAN FEDERATION OF GOVERNMENT EMPLOYEES

Ms. **Arnold**. I've been a claims representative since 1976, and like the other fellows, I have a very mixed—a lot of things that we have to do of which CDI's are only one of them.

I've prepared a statement and it turned out—I've listened to this morning's testimony—that quite a bit of what I had to say about the negative impact of this whole process, particularly on the mentally impaired, has really been covered quite well in other testimony. I just want to reiterate that that's the way it looks to us, too, from our position as seeing everybody who goes through this process.

[The prepared statement follows:]

Statement of Janet Arnold, Social Security Claims Representative, on Behalf of the American Federation of Government Employees

It goes without saying that the CDI process is a budget-cutting measure, one of a series of cutbacks in benefits to people, in favor of the Federal Government's current emphasis on military spending. Rather than address these priorities, I am here to talk about the CDI process itself.

The Administration would probably say that what is happening is a perfectly rational process. Disability beneficiaries are being re-examined and those who are no longer disabled are having their benefits terminated. But even those who actually have recovered are suffering greatly from this process.

My experience is that few beneficiaries believe they have recovered. So when they are told they are no longer disabled in the eyes of SSA and their check will be stopped in two months, it is a shock to the great majority of the beneficiaries. The Social Security Law does not take into account whether the terminated beneficiary can actually get hired, given the state of the economy. Employers who have a choice—and these days, employers generally can choose from among dozens of applicants for any given job opening—have no reason to choose to hire someone who believes himself to be disabled and who has spent three years or longer collecting disability benefits.

I work in the West Oakland Branch Office. West Oakland is basically a Black ghetto. Many of the middle-aged and older people I see in this CDI process are what I would call "bureaucratically illiterate." Most of them can read but cannot understand the government's forms and form letters. The face-to-face interview at the beginning of the CDI process helps somewhat in that we explain, more or less, what's at stake and the importance of cooperating with the various steps. But what do you think is the effect on people of being told there is an investigation underway to see if their checks should be stopped? Remember that nearly everyone being investigated feels that they cannot work.

They do not react calmly by going out and making sure their doctor prepares a detailed description of their medical problems so they can convince the bureaucracy they can continue to draw a check. Some people are very frightened; naturally. Since they know nobody is going to hire them, their survival as an independent person is at stake. Others are very angry. Many of the people I talk to have high blood pressure among their other problems; their doctors have warned them not to let themselves get excited or angry; the CDI process actually worsens the health of many beneficiaries. Many people show what I would call a mechanism of denial; they simply refuse to believe anyone is questioning their disability. This does not put them in an effective frame of mind for dealing with the CDI process.

When mental impairment in part of the problem, the difficulties are compounded. No matter what kind of due process is used—phone calls, registered letters, even the occasional personal visit to try to get the mentally impaired to make an appointment with a psychiatrist for a consultative exam—a lot of mentally ill people simply do not, and I would say cannot, follow through on the necessary steps. After all, that's why they're drawing benefits; they can't carry out simple orders. Many of the mentally impaired people among the poor and minority groups do not trust the mental health establishment. The cultural gap is too great. So, many of the mentally impaired do not have a regular psychiatrist they are seeing. Their benefits hang on one consultative exam with a psychiatrist who does not know them. That's why so many of the mentally impaired are being terminated. I think a major part of the CDI process is ceasing benefits to the worst off, those who cannot cope.

Many of the worst-off people have a representative payee, but this does not mean they necessarily have a literate, calm, concerned advocate. The representative payee for one middle-aged woman I saw recently, who was ceased because she did not keep her appointment for the C.E., was her 19-year-old son, who was so unconcerned with the whole matter of his mother's benefits that he had never bothered to tell us we were spelling his name wrong on the check, never bothered to tell us his mother was no longer on AFDC (once she got on SSI) and we should raise her check, and, true to form, didn't get her to the C.E., nor did he file an appeal on her behalf in time for her checks to be continued. Another fellow comes to mind who is so out of it that he has absolutely nothing resembling a permanent residence, he's in and out of Santa Rita county jail many times a year, absolutely none of his friends are willing to serve as his representative payee, and he picks up his Social Security and SSI checks at our office every month because that way we know he gets them and we also know he isn't in prison and is entitled to the check. Currently he's being investigated. Our only way to contact him is to wait for him to come to the office monthly. We have severe doubts that he will keep a C.E. appointment even if we make it while he's there. He will probably get ceased, but believe me, it isn't because he can work.

I want to quote from a Hearing decision on a 47-year old man who first got on Social Security Disability benefits in 1969 and then got on SSI too when that program began in 1974. He has a 10th grade education and worked as a warehouseman. He suffered gunshot wounds in 1969 and had a variety of physical and psychological impairments as a result. He claims he has not recovered. The judge spends several pages reviewing the evidence and then says,

"One should not experiment with people's lives. At the same time, realistically, there is no way now to know with certainty whether the claimant has improved to the point where he can undertake work activity or not except by removing the financial support of benefits and watching to see what occurs. . . . Although he still has some residual emotional problems, it may be that these would be helped by work activity. . . . I find the claimant physically and mentally currently capable of performing routinely structured light to sedentary work such as light custodial work without use of heavy buffers, light maintainance gardening, or factory and assembly work. . . . This sort of routine manual factory or custodial work is not the kind of work that involves much in the way of public contact or interaction with supervisors or co-workers anyway."

When I saw this man we had sent him a notice about the SSI overpayment that resulted from his benefits being continued until the Hearing and his losing the Hearing. At the time I saw him he had been without income for about two or three months. If "watching to see what occurs" is a fair test, what had occurred was nothing. The man was behind in his rent, had a PGE shutoff notice, was eating at his mother's place, and had not even gotten it together enough to get on General Assistance, let lone work. If he did decide to look for work he would be saying to a prospective employer, what amounts to, "Look, I got shot 13 years ago and I've never been the same since, but I can do light custodial work for you as long as I don't have to use the buffers and as long as nobody bugs me."

Of course different people react differently, but my experience in six years as a Claims Representative is that very few of the people we cease medically go to work. Many go on county welfare, either GA or AFDC; others live off relatives; some reapply until they get a softer judge and get back on benefits. It would be easy for the Social Security Administration to survey those who were ceased in, say, 1981, if the members of Congress actually want to know what has happened to the lives of the many people who have had their benefits terminated by this CDI process.

I feel that until the Federal Government is willing to guarantee jobs for all who cannot find work in the private sector, that to go on ceasing benefits to the disabled is to leave a lot of unfortunate people in a limbc with no actual means of supporting themselves.

Mr. STARK. Do you all know, when you interview someone, do you keep track if they go on to an appeal and the appeal is reversed or do you have any way of keeping track?

Ms. ARNOLD. It's basically done in pieces. In other words, in each of these is like a—it tends to get turned into a routine piece of paperwork, unfortunately.

Mr. STARK. So you don't know what your batting average is, but what I'm wondering, I've always wondered if we wouldn't get this things done a lot faster if we didn't move the decisionmaking process closer to the initial interview.

Ms. Arnold, I mean, how close do you come to hitting it? You must make the decision—maybe you don't have to mark it on the paper but to yourself, you must sit there and say, "Ah, ha, this person is cheating," or "Ah, ha, I don't think this person is going to work."

How accurate are you?

Ms. ARNOLD. Do you mean accurate in terms of the law?

Mr. STARK. No, accurate in terms of whether a person can go to work, or not.

Ms. ARNOLD. Mr. Stark, I think that the testimony this morning has made it extremely clear that most of the people who we turn down cannot go to work. In other words, the social security law which says that it's for paying those that are unable to work actually pays only a very small fraction of those who are unable to work. There is a vast number of people out there.

But if you mean in terms of after several years' experience, I'm quite good at guessing whether a person's going to get turned down. But that doesn't mean I agree with the decision.

Mr. STARK. How many cheats have you found in 6 years?

Ms. ARNOLD. Well, there are a small number of people who work and don't tell us, for instance. But the particular issue before us today——

Mr. STARK. What's the penalty if they get caught?

Ms. ARNOLD. They can be taken to court.

Mr. STARK. They can do time?

Ms. **Arnold**. But that's a very small number. The people we're talking about today, the people that are being medically reexamined, these are not people who have gone back to work and a great majority of these——

Mr. **Stark**. I'm inclined to agree with you but I just keep looking for the cheats because if we didn't have any cheats, if everybody was honest, then we'd just let them check the box, "Are you disabled or aren't you?" And then we wouldn't have to have all this——

Ms. **Arnold**. I think the point was made very well this morning that it's very difficult to fake a mental impairment because that involves years, in general, of being in and out of hospitals and in and out of crisis treatment at Highland Hospital on a Saturday night because the police have brought you there because your own brother called the police because of the way you're behaving or whatever. It's pretty hard to fake all that. And it's pretty hard to fake a physical impairment because, generally, those are backed up by X-rays and the rest of it. So it's hard to fake being impaired, mentally or physically. It's true that a small number of people do work and don't tell us. Yes, that does happen but in my experience, it's a very small number; 1 percent, maybe.

Mr. **Stark**. Doesn't that almost imply that the people who are hiring them are conspiring because it would be pretty difficult in time, to do what you're supposed to do about reporting income and withholding for social security and not have that cross-checked. So it seems to me that not only is the cheat, who, in quotations, is working and not telling you, the person who's hired that person probably has to be part of that scam, as well.

Ms. **Arnold**. We get lists. Unfortunately, it's a couple of years after the fact, but we do get a list that comes from what you said before. Each employer reports to the tax people and they report to us and that comes down to the local office and we get a list. We then have to call the people in and find out what's going on; are they still working, verify wages, working subsidies, and so forth, declare them overpaid, declare them, in many cases, recovered because the work amounts to enough to declare them recovered.

But I would say it could possibly be as many as 1 percent of our claimant load, probably less than that.

Mr. **Kelly**. You seem to be asking about, are there people who fake their disabilities to get on the rolls?

Mr. **Stark**. Well, a disability could be real by definition but that person might, through determination or good luck or special skills, be working. In fact somebody approached me, wanted to paint my house back in Washington. He said it had to be cash because he was collecting social security disability. I said he was just talking to the wrong guy. That's dishonest, I mean that's illegal.

Ms. **Arnold**. People who work that way don't make much money.

Mr. **Stark**. I can't imagine why you don't nab some of those people.

Mr. **Egerman**. What we have, is we have an Office of Program Integrity and whenever we find an abuse such as that, what we do is we have a form, which we would send it out to the Office of Program Integrity, who would conduct an investigation, tell us what information we need, and then they would consult with the U.S. attorney to determine whether or not a case would be prosecuted and what we have to go by, too, is any time a person signs an application, signs a CDI, they sign a penalty clause which states what the penalties are.

Ms. **Arnold**. You can get statistics on this. In fact, few people are prosecuted. I think you know this. Few of them can be prosecuted.

Mr. **Stark**. Well, they are sure getting written up.

Ms. **Arnold**. But there just aren't very many people that are doing what you're talking about.

Mr. **Stark**. I'm inclined to agree with you. That's my suspicion, as well. But I think as somebody earlier said that, basically, somehow there is this perception that if you're not working, the sign of the anti-Christ has struck you and you are philosophically not oriented to the free enterprise system and, therefore, you're not working.

Ms. **Reiter**. I'd like to return to that concept that you briefly introduced at the start of that question about the people who make the decision being closer to the interviewing process, because that's really important and there was an experiment—in fact, it's still continuing—to have the disability examiners in certain areas interview these claimants and make the decisions on the spot. And what they found was that there was a significant increase in approvals. When the people saw directly what the human effects were——

Mr. **Stark**. It would seem to me that any of the four of you on this panel could interview someone and make a decision immediately as to whether or not they are disabled.

Now, you might have to call for help if they brought you an X-ray. You and I probably are not able to read X-rays. Or if there is some medical testimony that's in four-syllable words which we would all have trouble pronouncing, you might have to call a medical person in and get some help, but I don't see——

Ms. **Reiter**. But, see, the overall stress of the bureaucracy is to remove decision making from the interviewers—to depersonalize it so that these applicants are no longer people. These are statistics on a piece of paper so it's easier to cut these people off, right like that. If the people that were making the decisions had to interview the claimants and could see them and could experience what their plight is like, the denial rate would be much lower.

Mr. **Stark**. We have the same trouble with wars.

Ms. **Arnold**. There is a measure that you could take through the administration, that Congress could take through the administration, that I think would present interesting data and I quoted in my written testimony an ALJ who said, "Well, we don't know whether this guy can work, or not, so we'll cut him off and find out."

Mr. **Stark**. That was an administrative law judge?

Ms. **Arnold**. That was a direct quote from an ALJ decision, which I have properly sanitized and crossed out all the names but I have it with me if you don't believe me.

Mr. **Stark**. I guess if you wanted to be that impersonal you could say, well, it's like teaching somebody to swim.

Ms. **Arnold**. Let's cut everybody off and see if they can work.

Mr. **Stark**. That seems to be what's been happening recently and, admittedly, the program is going to yield some savings by people who are just too intimidated or unable to respond to the bureaucracy.

Ms. **Arnold**. In the long-term, it doesn't really save us if they go on to GA, they get all the money that we spend.

Mr. **Stark**. What does it cost in California? It cost $30,000 a year to keep someone in the slammer, as opposed to $3,000 worth of SSI payments or $4,000. You know, that's 1 in 10. If 1 in 10 goes to jail, you've lost money. It's hard to measure. It's not like throwing away an MX missile. I can tell you exactly how far it will fly and how many people it will kill but it's much different to see how successful a program can be.

Ms. **Arnold**. But what you could do is survey, let us say, the people who were ceased in 1981 or the people that were ceased in 1982, and the Administration can do a computer run and get you those names and send them a letter and you will get a certain proportion of an answer to the letter. How many of them are working, and I'd be willing to bet it's a very small number, that most of them are either on General Assistance, AFDC, living off their relatives—those that haven't died in the meantime, that is. But very few of them are working and it's a survey you could have done. Congress could commission such a survey.

Mr. **Stark**. Carolyn, just as an aside, said that if we could do that even in years of unemployment, I mean, your idea of that survey might find that our high unemployment rate impacts even more and causes some distortion of that.

Mr. **Jensen**. Let me ask a question. You said you'd volunteer some information about the work plan. Do you have some comments about that? Or the plan of self-support.

Mr. **Kelly**. One thing I wanted to point out is that the plan for self-support is designed to exclude income so the person can maintain his SSI payments or build up his resources to buy cars and needs.

However, during the plan for self-support, we still continue to look at the trial work period and whether that person is doing substantial gainful activity. So although earnings might be excluded, in determining a person's payments, usually they are not excluded when you look and see if they have performed SGA. So in many cases, the plan for self-support cannot be extended past the 9 months and although the person may have a solution for the plan of self-support, it's still is terminated after about a year.

Mr. **Jensen**. The analogy is not perfect but the idea that some way you have a plan which recognizes trying to improve the person's situation——

Mr. **Kelly**. It seems they are very infrequently used, partly because so few of our claimants have any contact with the vocational rehabilitation department.

Over the 5 years that I've been a claims rep, I've said in my statement that probably only a half dozen had actually been in contact with vocational rehabilitation. The majority of our claimants never have any contact with vocational rehabilitation. And have no preparation for returning into the work force by the time their checks are stopped.

Mr. **Jensen**. The law does require that we refer to two vocational rehabilitations, if they are on disability.

Mr. **Kelly**. I'm not sure how that happens but, apparently, that doesn't filter down into the manual. I would assume that's done by the State disability, the disability determination service.

Ms. **Ladd**. At some point in the past, the local SSA offices were divided into specialized, title XVI, title II. Would you prefer that style of management or would you prefer or feel more comfortable with a generalized role?

Mr. **Egerman**. For a first line supervisor, that's how it is right now. At least in most offices, in terms of the district, that we usually have a title XVI supervisor and a title II supervisor.

But in terms of, you only have one particular person who handles disability, usually.

Ms. **Reiter**. One of the problems is, is that the amount of information that any claims rep or service rep is required to be on top of today is just incredible. We have a whole bookcase full of over 20 different manuals. They have to digest all that information. Several people pointed out that there wasn't that much publicity and there wasn't that much awareness in the offices of 1619 benefits.

The problem is, is that we might get a stack of transmittals on a daily basis that would cover 15 changes like this. I mean, we get transmittals that are sometimes 60 pages long. Maybe we get two or three of those in a day. In the meantime, there are 100 interviews waiting and you're interviewing all day; there isn't time to process the workload that there is. The pressures and the amount of information and the amount of workload is way too much for the resources available to handle them. One of the ways it was thought that we could cut down the pressure was to specialize functions so, really, it's about the only way to manage this unwieldly volume and complex workload.

Ms. **Ladd**. Except that when personnel are absent, the other people, the other claims reps, still have to do concurrent claims or have to step in and be able to do them.

I wanted to ask the claims reps if you're able to read all the transmittals that come through and, if not, how do you learn about the policy changes?

Ms. **Arnold**. If you just saw the volume we're talking about, you would know that that's impossible. Nobody could possibly read them all unless, of course, that's all they did. That is, there are some technical people, let's say reviewers, higher up in the hierarchy, who do, at times, read it all because that is all they do. But since we're interviewing from 9 to 4:30, no, we don't.

And how do we know about it? Well, we get training in the sense that, say, two or three mornings a week, someone who has been given an hour off interviewing, to read one of these things, then summarizes it for us, we read the cover sheets but the real way is, we look it up when we have to. And that's why there is this unfamiliarity that you run into.

Someone sits at my desk and says 1619 benefits, my reaction would be, this has been in effect a couple of years and I haven't had to learn it yet. That is, there hasn't been a situation yet, where when I got to that point, I actually had to look up that section because for one or another reason, they didn't fall under those amendments. I don't think those amendments are being carried out very much because they don't apply to very many people.

Mr. **Stark.** I'm going to have to intercede here. There is a bureaucracy that the staff is going to be faced with over at Budget-Rent-A-Car and United Airlines to get them back to Washington. They are unfamiliar with the airport and returning rental cars, and I do want to thank the witnesses. Some of the staff may want to talk with you more informally at a later date about the problem.

I want to thank all the witnesses, the mayor and city council for the hall, and my staff and the committee staff and Chairman Ford's staff for accommodating this hearing.

[Whereupon, at 11:55 a.m., the hearing was adjourned.]

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